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ABSTRACT

This monograph is the result of a study group on the rehabilitation service needs of unserved and underserved people with disabilities, especially those who are hard of hearing or have epilepsy. The first chapter discusses the criteria of the Rehabilitation Services Administration (RSA) for determining that members of a particular group are unserved or underserved and suggests modifications within the vocational rehabilitation system to enhance services to a specific group. The bulk of the document applies this model to persons who are hard of hearing or epileptic. For each disability group, a general discussion of myths and issues related to the disability is presented, followed by suggestions for needed modifications in the service delivery system in the areas of policy; practice; and training, education, and development. Finally, policy issues are discussed and specific recommendations offered for each of these two underserved populations. Seven appendices include: (1) a glossary; (2) the McCarthy-Alpiner Scale; (3) a Joint Statement of Principles of Cooperation of three organizations and the RSA concerning people who are hard of hearing; (4) the text of Section 36.303 of the Americans with Disabilities Act; (5) an outline of an inservice training curriculum for persons working with the hard-of-hearing; (6) a guide to communicating with people who are hard of hearing; and (7) a list of resource organizations. (DB)

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NINETEENTH INSTITUTE ON REHABILITATION ISSUES

SERVING THE UNDERSERVED - PRINCIPLES, PRACTICES, AND TECHNIQUES

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Report from the Study Group on

SERVING THE UNDERSERVED - PRINCIPLES, PRACTICES, AND TECHNIQUES

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Nineteenth Institute on Rehabilitation Issues

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Nineteenth Institute on Rehabilitation Issues

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The Institute on Rehabilitation Issues (IRI) has a long history of developing timely and meaningful documents pertaining to the field of rehabilitation. The intent of these documents is to provide rehabilitation professionals with a knowledge base which will enable them to provide quality services to individuals with disabilities. From the beginning, IRI documents have been used as preservice and in-service texts. It is expected that this year's document will lead to curriculum development at the university, Regional Rehabilitation Continuing Education Program (RRCEP), and state Vocational Rehabilitation Human Resources Department levels.

We commend the IRI sponsors--the Rehabilitation Services Administration (RSA), the Council of State Administrators in Vocational Rehabilitation (CSAVR), and the National Institute on Disability and Rehabilitation Research (NIDRR)--for their support of this valuable process. Additionally, we thank the Institute's Executive Committee for presenting the IRI Fellows with a challenging topic.

During the past year the Fellows in the Prime Study Group, who were the main contributors to this document, were faced with many challenges. One important challenge was to formulate a model which could be applied to any unserved/underserved group of individuals with disabilities. This task compounded the work at hand because the Fellows had to develop this model in a large group prior to completing their disability--specific tasks in smaller groups. Once the model was developed, they were able to proceed with applying and expanding upon this model for the two target groups, **Persons Who Are Hard of Hearing** and **Persons With Epilepsy**. The IRI Fellows gave unselfishly of themselves in accomplishing both tasks. We gratefully acknowledge the contribution of the Fellows in the Prime Study Group for their dedication to the development of this document.

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> ... the process taught me more than I ever knew about the areas that were addressed and has raised my awareness of issues I had not previously had to confront. It was one of the more interesting experiences I've been involved with and I am very grateful that I had the chance to participate and to meet the people most involved with the study.

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David (Dave) Corthell, Ed.D., Editor
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A Model

Chapter I

IMPROVING VOCATIONAL REHABILITATION SERVICES TO UNSERVED AND UNDERSERVED POPULATIONS

HISTORICAL PERSPECTIVE

Historically, the State/Federal Vocational Rehabilitation (VR) program has evolved from a vocational training program for veterans of World War I into a comprehensive program serving people with a broad range of impairments. In its first step toward greater inclusiveness, the vocational rehabilitation program expanded to incorporate civilians with physical disabilities (1920) shortly after its establishment as the Soldier's Rehabilitation Act in 1918. Over the years, other groups have received special mention in rehabilitation legislation such as people with spinal cord injury, mental illness, or mental retardation. During the early 1970s people with a history of criminal behavior and persons who were culturally disadvantaged became eligible for services. However, as priorities changed, these latter groups have become ineligible for vocational rehabilitation services unless they have a primary diagnosis of a severe disability.

In reviewing how different groups gained greater access to rehabilitation services, one finds that many factors were involved. Some client populations established their own access via personal advocacy efforts. Others gained the attention of the public and the vocational rehabilitation programs as a function of social trends (such as emphasis on people who were culturally disadvantaged during the 1960s) or advocacy on their behalf by notable public figures (such as the emphasis on mental retardation during the Kennedy era). Because priority groups are often identified via historical forces or public advocacy, the Rehabilitation Services Administration (RSA) has experienced varying degrees of control over the expansion or contraction of its own program. This historical pattern of changing priorities has strained vocational rehabilitation programs' capacities to serve certain populations effectively and left other groups unserved by the system.

The recent enactment of Americans with Disability Act (ADA) with significant impetus from consumers had a major impact on vocational rehabilitation. For example, ADA has caused significant changes to the Rehabilitation Act of 1973 through the amendments of 1992. These developments will further shape the delivery of rehabilitation services into the twenty-first century.

A PROACTIVE APPROACH

The Rehabilitation Services Administration has attempted to respond proactively to assure that fair access and quality services are available to all groups of people with disabilities. To further this effort, RSA has developed its own definitions of unserved and underserved populations. RSA has listed specific criteria for determining whether these populations exist.

RSA intended that the definitions and criteria apply to specific disability populations or subsets of populations. The definitions were not intended as selection criteria for a single individual with a disability. At any given time, a person may make a compelling case that he or she should be considered unserved or underserved. However, efficient planning at a national level cannot be conducted on such a microlevel.

The IRI Study Group agrees with RSA's distinction between unserved and underserved populations. However, the IRI authors have chosen to expand the RSA concept of access and adequacy of services. It is seen as a continuum encompassing populations that are (a) unserved, (b) underserved, and (c) adequately served. This document focuses on disability populations that occupy the unserved/underserved segment of the continuum.

The Unserved/Underserved Status: RSA Perspective

RSA defines "unserved" populations as groups of individuals with disabilities who are not served as the result of a variety of policy, practice, and environmental barriers. Barriers contributing to a state of being unserved include:

1. Implementation of an order of selection
2. Waiting lists for services
3. Lack of referral to or identification by the vocational rehabilitation system
4. Lack of resources--either nonavailability of service to address needs or nonavailability of funding for services
5. Lack of available/accessible transportation

A number of criteria for identifying an unserved population may be used. To be considered unserved, a population must qualify on the basis of one or more of the following:

1. Number of individuals in nonpriority categories under order of selection
2. Number of individuals on waiting lists
3. Number of individuals contacting Client Assistance Programs (CAPs) regarding lack of access to services
4. Number of vocational rehabilitation cases closed due to lack of transportation

RSA defines "underserved" populations as groups of individuals with disabilities who are inadequately served as a result of one or more of the following barriers:

1. Racial/ethnic issues and barriers
2. Communication barriers

3. Attitudes of service delivery personnel and the general public

4. Lack of outreach to population with a specific disability

5. Geographic dispersement, especially in rural and urban poverty areas

6. Lack of service resources to meet particular needs of new/emerging disability populations

7. Lack of extended service resources for ongoing support

8. Depressed economy/job market

A group with disabilities must possess one or more of the following criteria of identification before inclusion as an "underserved" population:

1. Significantly lower percentage in vocational rehabilitation caseload than percentage in general populations (e.g., sex, race, age, ethnic background, educational level)

2. Significantly lower percentage in vocational rehabilitation caseload than expected based on best estimates available on prevalence of disability in general population

3. Substantiation by data available from constituent groups

4. Verification through review of existing research findings and other literature

The Unserved/Underserved Status: IRI Perspective

The IRI Fellows accept the RSA definitions and standards as a starting point. They will aid in the determination of whether particular population groups have access to and effective assistance from rehabilitation services. Based on their experience with rehabilitation and people with disabilities, IRI members believe that additional criteria of inclusion are relevant in making the case that a certain group is unserved/underserved.

People in specific disability groups may be unserved or underserved because the nature of their condition presents challenges of a unique nature. They may experience a level of social stigma and misunderstanding which denies them fair access to social and employment opportunities. They may require reasonable accommodations in the service delivery setting which are infrequently available. A detailed list follows of additional conditions that are germane to the task of identifying unserved and underserved groups (a brief rationale for including each entry on the list is provided):

1. **Invisibility of condition**. People with hidden disabilities (e.g., hard of hearing) are often viewed as less severely disabled than people with visible disabilities (e.g., amputation) because they appear to have no significant functional limitations.

2. **Accommodation/technology needs**. Misunderstanding the impact of a disability on individual functioning causes service delivery systems to overlook the accommodations that the person needs (e.g., facing the person when speaking, FM amplifiers).

3. **Personal misconceptions about the disability**. Some individuals with a particular type of disability may hold the same misconceptions and prejudices that are held by the general public and thus will not seek assistance.

4. **Denial of the condition**. To avoid negative social feedback, members of some disability groups are unwilling to self-identify. Thus, incidence and prevalence figures are artificially low, and a collective group identity for advocacy purposes fails to develop.

5. **Lack of awareness of prevalence/incidence of condition**. For some disabilities, epidemiological research is insufficient to provide an accurate estimation of the prevalence and incidence of the condition. Therefore, it is impossible to estimate the extent of the group and the extent of its being unserved or underserved. Accuracy problems with incidence and prevalence estimates are exacerbated by unwillingness to disclose existence of a disability (see #4 above).

6. **Lack of awareness about vocational rehabilitation services**. People cannot access services of which they are unaware.

7. **Confusion with similar disabilities**. To the uninitiated, some disabilities appear to be very similar in nature. However, treating them in such a manner does not result in optimal outcomes for the groups in question.

8. **Lack of prevocational/youth services**. Inadequate funding for developmental programs creates two types of problems: For youth with disabilities, preventable problems are not addressed. As adults, these individuals not only face more serious problems but also lack the readiness for adult interventions such as vocational training and placement.

9. **Secondary health problems**. Some conditions are secondary to another serious disability leaving the individual with twice the disability-related problems to overcome (e.g., diabetic retinopathy or substance abuse leading to traumatic brain injury and/or epilepsy).

10. **Overidentification with the disability**. Negative developmental experiences and continued social stigma have a cumulative effect on the individual's level of self-confidence. In turn this may cause the person to adopt self-limiting perceptions which compound the environmental barriers presented by the disability.

11. **Identification of the condition as a "secondary disability."** The term "secondary disability" suggests to some service delivery personnel that a condition does not merit their full attention.

12. **Policies**. "Order of selection" based on severity of disability can preclude service to populations of individuals whose disability is not listed as among those designated as severe. However, they may have severe functional limitations.

13. **Difficulty in establishing functional limitations**. Some conditions are severe but present difficulty establishing functional limitations due to interventions. The persons currently appear to be functioning well; however, without assistance their functioning may change.

14. **Use of arbitrary eligibility standards**. State vocational rehabilitation programs establish their own guidelines on eligibility based on federal policy. These guidelines vary from state to state. As a result, a person with a particular disability may be eligible for vocational rehabilitation services in one state but not in another.

15. **Lack of research on "best practices."** Failure to fund demonstration projects that experiment with innovative service techniques results in lack of shared knowledge about effective services to different disability groups.

16. **Lack of sensitivity**. The medical community including allied health professionals are often uninformed about the potential of people with a certain type of disability. They lack knowledge about the services available which may assist persons with disabilities. As a result the person with a disability may not be the referred to a rehabilitation program.

17. **Need for personal empowerment**. Some individuals, as a result of the unpredictability of their disability, may experience psychosocial coping problems. Without intervention, the persons may passively accept an unnecessarily limited lifestyle.

18. **Lack of training**. Lack of knowledge among service delivery personnel of effective medical, rehabilitation, and placement strategies may consign some people to an underserved status. Failure to include certain disabilities as topics for research and training efforts is an important contributor to a state of underservice.

19. **Increased psychopathology compounded by stigma**. Some conditions increase the probability that a person will experience severe psychological difficulties. These difficulties are then compounded by significant environmental stressors such as continual physical barriers or social stigma.

20. **Barriers to employment**. People with disabilities generally face stereotypes that cast them as less than capable in social and vocational roles. However, some disabilities evoke even stronger stereotypes (e.g., epilepsy). These stereotypes lead to negative attitudes by the people who control access to training, rehabilitation, employment, and other types of gainful activity.

Factors Contributing to Being Unserved or Underserved

Criteria for identifying unserved/underserved disability populations provided by RSA and the IRI document are summarized in Table I-1. The Institute's Prime Study Group has used these criteria to frame an argument that persons who are hard of hearing and persons with epilepsy are unserved/underserved. Steps in generating an argument include:

1. Selection of various factors contributing to being unserved/underserved.

2. Preparation of rationale as to why one or more factors contribute to the problem of being unserved or underserved.

3. Presentation of these rationale to appropriate service provider administrators or advisory groups (e.g., state vocational rehabilitation agencies, RSA) for setting priorities of services and action.

Table I-1 summarizes the criteria that were used to develop this argument. The criteria are divided into four categories: demographics, disability, psychosocial, and service delivery system factors. Check marks on the table show which criteria describe underserved persons in this argument.

People who are hard of hearing and people who have epilepsy are presented as examples of unserved/underserved groups of individuals. The rationale for this position is developed in the remainder of the document.

THE MODEL

The charge to this Prime Study Group was to develop a model for determining if a population is unserved or underserved. The 31 criteria identified in Table I-1 can be used as a vehicle for enhancing services to members of disability populations which are unserved or underserved. The 31 factors provide a useful basis for RSA to proactively identify such populations and for advocacy groups to justify that a particular disability group is unserved or underserved. When such identification is established, it becomes incumbent on the service delivery system to respond at a variety of levels including federal and state policies, case service practices, and in-service and preservice training programs. As such, the model presented herein focuses, first, on strategies for identifying and justifying that certain populations are unserved or underserved and, second, on identifying segments of the service delivery system in which changes or accommodations may be needed in order to appropriately respond to the targeted disability population.

Developing a Case for Being Unserved or Underserved

The first step in applying the model involves considerable effort on the part of those who advocate that the particular group is unserved or underserved. Such an effort begins with developing proof of being unserved or underserved according to the RSA criteria. Proof can

Table I-1
Criteria Contributing to being Underserved

Criteria	Disability Groups	
	Hard of Hearing	Epilepsy
Demographics		
Racial/ethnic issues	✓	✓
Geographic dispersement	✓	✓
Lack of prevalence/incidence data	✓	✓
Disability		
Communication barriers	✓	○
Invisibility of condition	✓	✓
Confusion with other disabilities	✓	✓
Secondary health problems	✓	✓
Psychosocial		
Attitudes: Service delivery personnel and public (stigma)	✓	✓
Depressed economy	✓	✓
Personal misconceptions	✓	✓
Denial	✓	✓
Lack of awareness about VR services	✓	✓
Overidentification with the disability	○	✓
Need for personal empowerment	✓	✓
Employment barriers	✓	✓
Service Delivery		
Order of selection	✓	✓
Waiting lists	✓	✓
Lack of referral/identification	✓	✓
Lack of resources	✓	✓
Lack of transportation	○	✓
Lack of outreach	✓	✓
Lack of extended service resources	✓	✓
Lack of accommodations in service delivery process	✓	○
Lack of prevocational/youth services	✓	✓
Label of "secondary" disability	○	✓
Difficulty establishing functional limitations	✓	✓
Arbitrary/inappropriate eligibility and accountability standards	✓	✓
Lack of research on "best practices"	✓	✓
Lack of awareness among medical providers	✓	✓
Lack of provider training	✓	✓

be obtained by accessing existing data or information and/or by generating new information. For many disability populations which are unserved or underserved, existing information may be inadequate to support fully a case for improving services to that population.

Advocacy organizations can be an important source of information regarding specific disabilities. Often, these groups not only amass published information related to the disability but also gather prevalence data and/or document the need for additional services themselves. In these instances, advocates may wish to embark on the process of generating new data by conducting needs assessment studies. Finally, it may be helpful for advocates to research strategies which have been effectively used by other disability populations in demonstrating their status as unserved or underserved. These strategies include various kinds of advocacy efforts ranging from providing public information to lobbying at the national level.

Some disability populations have been successful in securing enhanced services by mobilizing the families of individuals with a particular disability as spokespersons and advocates. Still other populations have benefitted from instituting state-level and/or national mandatory reporting systems or registries in order to demonstrate the incidence of the specific disability. Other strategies have included designating specialized counselors and/or state coordinators who focus on a specific disability within the state-federal vocational rehabilitation system. Having specialized counselors often enables the system to identify a greater number of individuals who are desirous of receiving services but who have been reluctant to enter the system because of a fear that their needs would not be met. Research can also be conducted to demonstrate the cost-effectiveness of services which have been provided pointing to favorable outcomes such as competitive employment, reduction of dependence on public aid and Social Security payments, and contribution to the tax base.

Developing Suggestions for Enhancing the Delivery of Services

Once a case has been made that a particular disability population is underserved according to the RSA and IRI criteria, it then becomes incumbent upon advocates for that population to give constructive suggestions to the service delivery system as to how to include and better serve the population. Advocates need to develop specific recommendations in three general issues categories: (a) policy; (b) practice; and (c) training, education, and development. In order to assist advocates in building specific recommendations, this Prime Study Group has identified a number of factors in each of these three categories which are typically of concern to unserved or underserved populations.

Policy Issues. Issues related to policy at both the national and state levels are often of concern to disability groups. Service delivery practices are also affected by policy outlined by the federal and state programs. For example, policies related to order of selection may inadvertently exclude some individuals from receiving needed services as may policies related to the definition of severe disabilities. Also, policies related to order of selection mandate that state agencies serve first those persons who have severe disabilities.

Another eligibility issue which may be troublesome relates to the definition of substantial impediment to employment. Members of some disability populations believe that they are unserved or underserved and that their disability does, in fact, interfere with obtaining and

maintaining gainful employment. However, the agency or specific agency counselors may not agree.

Still other disability populations cite difficulties in obtaining needed services which result from the medical coding system. In such instances, no code or insufficient coding may make it difficult to document the need for additional services and/or to monitor the effectiveness of services rendered to the population.

Federal priorities related to research also affect unserved and underserved populations. Researchers may be discouraged from embarking on or pursuing studies related to a particular population when federal priorities exclude or inadequately focus on that group. Without access to adequate research findings, it is difficult for an unserved or underserved group to document its status. A lack of research on issues related to a particular disability may also impede the improvement of services to that population, particularly when little information exists regarding the most effective methods of providing services to that population.

In some cases, the organizational structure of the state-federal vocational rehabilitation system may contribute to maintaining a condition of being unserved or underserved. Some disability groups have found it useful to advocate for a special office within RSA that focuses on enhancing services to a specific disability population as in the Office on Deafness and Communicative Disorders. It is not feasible to set up an office for each disability. However, it may be advantageous to consider some type of administrative office that has oversight regarding disability populations that are at risk of being unserved or underserved. This type of strategy may be particularly helpful with "hidden" disabilities, i.e., those which are not readily visible and easily identified. In these cases, efforts may be needed to increase awareness and sensitivity toward unserved and underserved populations among federal planners and policy makers.

Inadequate involvement of consumers and advocacy groups at the federal level has also been a stumbling block for some unserved and underserved groups. The requirement of the state rehabilitation advisory council may help resolve this concern.

Accessibility of vocational rehabilitation offices for a particular disability population is of concern in ensuring adequate services. Offices need to be located where consumers can reach them with consideration being given to geographic dispersement and availability of accessible transportation. Office space needs to be fully accessible with appropriate accommodations for communication differences and needs.

Funds will be needed for replicating model service delivery systems for unserved and underserved populations. Additionally, cooperative agreements are helpful in ensuring that the expertise developed in model programs is provided in partnership with consumer or advocacy organizations. It is also imperative that in-service training funds be allocated so as to increase the knowledge and skills of service providers in reference to unserved and underserved populations.

Finally, program evaluation strategies need to be implemented to track the effectiveness of service delivery to unserved and underserved populations. In order to enhance services, it is

incumbent upon the state agency to track the effectiveness and efficiency of services to these groups and to empirically monitor improvements in service delivery.

Practice Issues. Practices need modification or enhancement at each stage of the rehabilitation process in order to ensure adequate delivery of services. For example, case finding efforts are need with unserved and underserved groups. Case finding should begin even if the agency has a waiting list for services and is not actively involved in additional outreach efforts. Members of unserved and underserved disability groups are often not aware of services which are available to them. Or, they are hesitant to access services as the result of misconceptions or stereotypes of the vocational rehabilitation process. If either or both are true, extensive outreach efforts are necessary in order to inform and reassure the members of targeted disability groups.

Once members of unserved and underserved groups access the vocational rehabilitation system, it is essential that the entire vocational rehabilitation process accommodate the unique needs of each group. Intake procedures need to be appropriate; intake settings should be physically accessible; and the client's communication needs must be met. Diagnostic procedures need modification and/or new resources should be developed in order to enable appropriate assessments of the clients' strengths and liabilities. Highly individualized and comprehensive assessment instruments are necessary as opposed to the use of a medically-oriented diagnostic system for all clients.

Specific resources for technology, which will benefit individuals with the specific disability, are developed. Counseling techniques are modified, and channels of communication are opened between the counselor and the client so that issues related to the disability are freely examined if the client so chooses.

Innovative approaches to placement are warranted for members of unserved or underserved disability groups. Nontraditional employment strategies may be needed as well as extended forms of support in employment. For some groups, postemployment services are necessary to provide extended support, ensure retention, and open pathways for promotion and career growth.

Training/Education/Development Issues. It is necessary to provide opportunities for professionals throughout the service delivery system to increase their knowledge about unserved and underserved populations. Strategies for enhancing training, education, and development can be initiated by several segments of the vocational rehabilitation system. RSA can establish training priorities for short- and long-term training grants. When the training of specialists is not warranted, efforts are made to examine how information related to specific unserved or underserved populations is infused into existing university curricula. The preservice training programs are encouraged to develop and field test model curricula and to disseminate them to all training programs. RSA staff may also benefit from training opportunities which would enhance their own knowledge of these populations.

Both the National Institute on Disability and Rehabilitation Research (NIDRR) research priorities and RSA special projects and demonstration grants should address issues related to underserved populations. Particular emphasis is placed on the importance of disseminating findings that increase the base of knowledge regarding populations identified as unserved or

underserved. Regional Rehabilitation Continuing Education Programs (RRCEPs) should be encouraged to disseminate products and information developed by Research and Training Centers and other research which relate specifically to unserved and underserved populations.

Education is also needed for administrators and first-line supervisors to sensitize them to the needs of members of unserved and underserved disability groups. Administrators and supervisors need the information so they can modify the service delivery system in order to enhance services to these groups.

CONCLUSION

This chapter has outlined a rationale for developing a case that members of a particular disability group are unserved or underserved according to the RSA criteria. It has also suggested areas within the overall vocational rehabilitation system where modifications may be necessary in order to enhance services to a specific group. These suggestions have, thus far, been presented in only a generic sense with the intent of providing parameters which advocates for a particular disability group could examine and use as a point of departure in developing their own case for enhanced services.

The following two sections of this document demonstrate the application of this model to two specific disability populations: persons who are hard of hearing and persons with epilepsy. For each disability group, a general discussion of myths and issues related to the disability is presented, followed by suggestions for needed modifications in the service delivery system in the areas of policy; practice; and training, education,and development. Finally, policy issues are discussed and specific recommendations are presented for each of these two underserved populations.

Serving People Who Are Hard Of Hearing

Chapter II

PEOPLE WHO ARE HARD OF HEARING

An Underserved Disability Group

The purpose of this chapter is to present background information important in the delivery of quality rehabilitation services. It will present the definition of hearing loss and begin to identify the various factors contributing to being unserved or underserved. Additional factors such as demographics, employment trend, service delivery practices prepare the rationale to support the argument that persons who are hard of hearing are at risk of not receiving any or receiving less than adequate services.

As they do with many persons with disabilities, the practitioners must look beyond the medical condition and functional impairments to the complex environmental barriers: social stigma; discrimination; and lack of knowledge, training, and basic communication access. This chapter will demonstrate that the hard of hearing population merits a second look, not a view clouded by stereotypes, biases, and misinformation. The reader will be encouraged to approach this diverse population with a "new or improved" perspective--one based on a genuine interest and wish to learn enough about the hard of hearing population to make a difference.

HARD OF HEARING: DEFINITIONS OF DISABILITY

The Rehabilitation Services Administration (RSA) defines hard of hearing as "a hearing impairment resulting in a functional loss, but not to the extent that the individual must depend primarily on visual communication" (RSA Statistics, 1991). The report extends the definition by requiring the following three evaluations before reporting a person who is hard of hearing as severely disabled. Unfortunately, specific levels of loss are not specified and are left to interpretation by the state rehabilitation agency. In addition, functional issues must be considered. (The vagueness of this determination of severe disability is further discussed in Chapter V.)

1. **Speech Reception Threshold (SRT)**: The softest level of sound at which a client can correctly respond to at least 50 percent of a list of spondee (bi-syllabic) words.

2. **Pure Tone Average (PTA)**: PTA scores are determined computing the average

pure tone thresholds at 500 Hz, 1000 Hz, and 2000 Hz. For example, if the thresholds are 60 dB at 500 Hz, 80 dB at 1000 Hz, and 90 dB at 2000 Hz, the pure tone average would be 77 dB (60 + 80 + 90 divided by 3).

3. **Speech Discrimination**: A phonetically balanced word list is to be administered at the person's maximum comfort level to determine the individual's level of speech determination.

However, "hard of hearing" is much more that this clinical examination of hearing loss. hearing ability is measured in SRT, PTA, and Speech Discrimination. However, it is also influenced by nonclinical factors such as the client's ability to communicate (El-Khimai, 1986). The factors used in determination of whether a person with a hearing impairment is hard of hearing is based on medical diagnostic assessment. However, it also uses the client's perceived limitations caused by the hearing impairment as part of the assessment of functional limitations.

In Table II-1, the degree of hearing loss in the speech range identifies variations of loss that affect not only speech patterns and speech discrimination but, most importantly, the ability to learn, socialize, and adjust to the total environment (Porter, 1975).

Table II-1
Degree of Hearing Loss in the Speech Range (ISO)

A. **Slight loss**: loss of 20 decibels or less. Generally unnoticed; faint whispers may not be understood.

B. **Moderate loss**: 20-40 decibel loss. Difficulty in hearing when tired or inattentive; in distant theater seats; in the noise of general conversation; when articulation is soft or poor.

C. **Marked loss**: 40-60 decibel loss. Considerable difficulty in hearing conversation unless voice of speaker is raised, distance is small, and conversation is with one person.

D. **Severe loss**: 60-80 decibel loss. Extreme difficulty in understanding even shouted conversation. Speech and language cannot be learned normally by children with this amount of loss.

E. **Profound loss**: over 80 decibel loss. Extreme difficulty not only in understanding shouted conversation but even in hearing the sound of the voice.

Orientation to Deafness
Deaf Reference, 1978

Causes of Loss

Hearing impairments result from disease, trauma (including aural trauma), congenital causes, and unknown factors. These can cause neurological (sensorineural) deafness, conductive hearing loss, and mixed (conductive and congenital-neural) hearing loss. Hearing loss can be caused by tumors or brain damage from conditions such as cerebral hemorrhages that affect the auditory pathways from the auditory nerve through the brain to the outer temporal lobe (Orientation to Deafness, 1978; Porter, 1975).

Treatment Issues

Otitis media (infection of the middle ear) and otosclerosis (calcification of the bones of the middle ear) are examples of diseases that can cause conductive hearing losses. They can be treated by either surgery or other state-of-the-art technological treatments (Karmody, 1986).

Medical treatment for sensorineural hearing loss is rarely of value. Sensorineural hearing loss is generally treated with hearing aids, which are helpful but limited. Simply put, and unlike eye glasses, a hearing aid is only an amplifier of sound. It does not restore normal hearing. It typically amplifies all sound including background noise, not just speech.

Language Acquisition in Relation to Vocational Functional Limitations

The age of the client at the onset of hearing impairment is an important component to his/her language acquisition, extent of communication, educational achievement, and vocational objective determination. For a discussion of how hearing **alters** language acquisition, the reader is referred to Kretschmer and Kretschmer (1986). The problem of communication effectiveness will depend upon the time of onset of the loss and/or how early the loss was diagnosed and treated:

> In **moderate impairment**, if the problem began before language and speech were fully developed, and habilitation/rehabilitation measures were not employed, . . . both speech and language may be impaired . . .
>
> The effects of **severe hearing impairment** . . . language will probably be affected. The means of understanding may be dependent upon hearing with use of (aids) . . . The primary means of communication may shift from speaking-hearing because auditory discrimination is affected to some degree (Porter, 1975).

Table II-2 outlines the various categories in differential onsets of hearing loss. The terms prevocational and postvocational are RSA terms indicating whether or not the person was employed prior to the hearing loss (RSA, 1991).

Vocational functional limitations determine to what degree the level of hearing loss will affect placement efforts. It is based on reports by the rehabilitation counselor, otological/audiological medical reports, and the person's perception of vocational interference

Table II-2
Differential Onsets of Hearing Loss

1. Prenatal	**Before birth**: heredity, maternal illness, infection.
2. Natal	**At birth**: anoxia, birth injuries, infection, accident.
3. Postnatal	**After birth**: childhood illnesses and accidents.
4. Prelingual	Before language is learned (usually interpreted to mean before 4 years of age).
5. Postlingual	After language is learned.
6. Prevocational	Before beginning a career (interpreted as prior to 19 years of age).
7. Postvocational	After initiating a career (after 19 years of age).

Orientation to Deafness
Deaf Reference, 1978

(of hearing, i.e., residual hearing). Usually functional limitations will not result in substantial vocational impairment with:

1. No functional hearing in one ear but with a mild hearing impairment in the other ear.

2. An unaided loss of less than 25 decibels in the speech range in each ear.

(Michigan Casework Operations, 1992)

A tool used in Michigan as an aid to determine functional limitation in cases of hearing loss is the McCarthy-Alpiner Scale (see Appendix B). The form, completed by the client and the counselor, can be used by the medical examiner for validating the medical results of loss. It can also be used by the counselor to act as a guide for assessing vocational limitations or barriers to employment (Michigan Casework Operations, 1992). Consideration should be given to the effects of impaired hearing in occupational settings such as impaired ability to localize sounds, which have a direct bearing in relationship to his occupational environment and job duties (DeLorier, 1977).

Consumers define "hard of hearing" as persons having a hearing loss ranging from mild to profound but who can still benefit from amplification. Their speech is adequate for

communication, and they use, however imperfectly, the auditory mode to receive communications.

An invisible condition without external evidence, such as signing, places people who are hard of hearing in limbo (Stone, 1987). From an audiological perspective, the effects of a 50 dB hearing loss seem less problematic than the effects of a 90 dB loss, or deafness. This is further implied by the definition of a person who is hard of hearing as one who, generally with the use of a hearing aid, has residual hearing sufficient to enable **successful** processing of linguistic information through audition. However, when secondary rehabilitation needs are considered, it becomes apparent that the definition minimizes adjustment problems of many persons who are hard of hearing, who often are **not successful** at processing linguistic information (Harvey, 1989).

The distinction among "hard of hearing," "deaf," or "hearing-impaired" often depends upon the viewpoint of a given professional, policy, social indicator, or audiological criteria. There is no standard definition to help rehabilitation specialists decide which hard-of-hearing person has an impairment which seriously limits one or more functional capacities in terms of employment.

Problems with definitions are first felt by people who are hard of hearing when they present themselves for services. The federal-state rehabilitation program uses a coding system which is exclusionary to hard of hearing persons (i.e., 55 dB loss or greater to be coded severely disabled).

For example, most "deaf" persons in these United States are not deaf but are actually "late deafened adults" (Schein & Delk, 1974; Brown, 1991). Many lose their hearing rapidly and do not know sign language. Because they don't know or use sign language does not mean they are less in need of assistance.

PSYCHOSOCIAL ISSUES

An estimated two million people in the United States are categorized as deaf. An additional 18 million persons who are hard of hearing must cope and adjust to uninvited onset of hearing loss" (Orlans & Meadow-Orlans, 1985). Helen Luey (1986) points out that "hearing loss is no respecter of personality, social skills, supports, or status."

This segment on psychosocial factors to hearing loss addresses the characteristics and behaviors that are prevalent in persons with severe hearing loss. The onset of hearing loss impacts on the natural developmental process of an individual. It impacts on the individual's self-identification, family interaction, societal expectations, and coping mechanisms. In short, it interfere with rehabilitation planning and vocational adjustment.

The psychological and sociological dynamics that affect individuals with hearing loss impact on all components of personal and life development. The diagnosis of hearing loss, no matter when the age of onset, places the person and family in a complex state of emotions that may take several years of adjustment that may or may not succeed. Ramsdell (1963) points out

that hearing loss produces a psychological impairment more basic and severe than the difficulty in communication. Adjusting to a hearing loss can parallel the typical reaction to severe disability where the stages of recovery follow the pattern of shock, denial, anger, and finally adjustment.

Denial is the primary reaction to hearing loss. For example, "You talk too softly " or "It's too noisy for anyone to hear" are typical comments. The denial factor further results in isolation and withdrawal from society for the afflicted. The underservedness is, in part, self-induced in that some individuals refuse referral to rehabilitation during this stage of recovery. The person who is hard of hearing is constantly seeking the right balance between accepting responsibility and asking for help (Luey, 1986). This search is due to adverse cultural attitudes and ignorance about the nature of hearing loss itself (Gilmore, 1982). The individual is influenced by reaction from medical and allied health and mental health agencies (Johnstone, 1991-92). The family's lack of acceptance also contributes to the gap between outreach and rehabilitation as well as to psychosocial adjustment.

The isolation and withdrawal feature presents outreach challenges for the vocational rehabilitation practitioner. The inability to identify the hard-of-hearing population--unlike the deaf community which has a defined cultural base from which to tap--presents problems for case finding efforts. Difficulty in identifying the group also presents challenges to the vocational rehabilitation practitioner to best determine the needs of this group, particularly for developing case management and best practices strategies.

Common forms of behavior among people with impaired hearing are avoidance, fear of being misunderstood, breakdown of communication, withdrawal, mounting problems with telephone usage, social and recreational withdrawal, mood swings, anger, guilt, depression, and feeling "left-out" (Himbel, 1989; Johnstone, 1991-92). In short, hearing loss is intrusive in all facets of life. Persons with reduced hearing are not a psychologically homogeneous group (Meadow-Orlans, 1985; Stone, 1987). The psychological effects include depression and withdrawal with resultant isolation, as well as irritability, fatigue, nervousness, fearfulness, and anxiety (Thomas & Herbst, 1980; Thomas, 1984; U.S. Congress, 1986; Vesterager, Salomon, & Jagd, 1988). Aside from receptive communication barriers, secondary problems reported by hard-of-hearing people include feelings of depression (not necessarily at the clinical level), suspiciousness, peculiar and serious personality changes, and feelings of rejection. Ramsdell (1978) described three psychological levels of hearing: (a) the social level (to communicate, use language); (b) the signal, or warning level; and (c) the most basic level, the auditory background of all daily living. These incidental background noises maintain our feeling of being part of a living world and contribute to our own sense of being alive.

The symptoms that a person who is hard of hearing exhibits are determined, in part, by the environment in which that person lives. The level of acceptance and coping mechanism play an integral role in the person's ability to cope later in life. The underserved category would best identify the unidentifiable; how the hard of hearing population, who by nature of their experience, will react to the mainstream.

For the person who is deaf or hard of hearing, rejection becomes a way of life (Low, Dalecki, & Alan, 1991). There becomes a subconscious way of life which degenerates into

passivity and not belonging. These characteristics and attitudes filter into the work place if the individual is employed at the time the hearing loss occurs. Therefore, in an employment situation, certain behaviors observed by hearing co-workers of the hard-of-hearing worker may be seen as expressions of stubbornness, arrogance, or absent-mindedness (Reichtberg, 1989). However, they are coping mechanisms the persons have learned to use in order to adjust to a particular environment. Lack of assertiveness in addressing their needs in the worksite, staying in their positions or tasks after acquiring skills that could lead them into other challenging job tasks, or quitting the job are ways in which the persons "may simply relinquish their jobs rather than fight through the adjustment process needed to keep them in the work force as productive employees" (Melton, personal communication, 1989).

The individuals with a hearing impairment struggle to position themselves in the family unit. Family members complain of high levels of noise (e.g., TV or radio turned up), constantly asking the individual to repeat, or becoming frustrated when attempts with communication become difficult. These problems eventually motivate the person to seek help.

That the person who is hard of hearing has negative attitudes and difficulty accepting his/her own hearing loss is a reflection of prevailing societal attitudes (Ramsdell, 1978). The stigma associated with hearing loss encourages people who are hard of hearing to hide their hearing loss and consequently not seek help. The attitudes of the hearing public, including many rehabilitation people, set up a system of negative reinforcement, whereby these societal attitudes and behaviors (employment discrimination, prejudice, irritability, patronizing behaviors, bewilderment, etc.) encourage people who are hard of hearing to be evasive about their hearing loss. Younger persons who are hard of hearing and hearing people equate hearing aid use with aging which has a secondary negative connotation to this diminished physical capacity.

Family members may not comprehend, nor have the knowledge of available resources, or support mechanisms that can help the individuals work through the dynamics of their grieving process. Denial reactions of the family manifest by becoming reactive, i.e., rejection of the person with hearing loss by ignoring the issues. Rejection may be as subtle as brushing away the individual's attempts at participation in family discussions by ignoring the responses or withdrawing from the afflicted family member with fears that this may happen to them (Johnstone, 1991-92).

Individuals who are hard of hearing become frustrated with professionals "who should know better" (Johnstone, 1991-92). The lack of sensitivity to or knowledge of hearing loss by medical and allied health care officials, who do not remain current on the techniques and strategies for adjusting to hearing loss, is resented. Their inability to provide resources or address the problem is a common complaint by the person who seeks help.

Most importantly, the social self-concept of the person who is hard of hearing is not the same as the social self-concept of the person who is deaf. Both have similarities in terms of degree of hearing loss, level of education, and the difficulties they face. However, deaf communities have developed out of a response to negative experiences whereby the hard of hearing who try to deny or hide their losses tend not to join organizations and make efforts to blend into the hearing world (Weisel & Reichstein, 1990).

Less than one percent of the persons who are hard of hearing learn sign language. The hard of hearing population, unless currently familiar or part of the deaf community, is estranged from that particular cultural base (Stone & Fennell, 1990). Communication facilitation, or methods used to develop the communication process, is the determining factor in building self-esteem. Referral to an aural rehabilitation specialist with periodic follow-up on the client's progress may be in order. The rehabilitation counselor needs to work with the aural rehabilitation specialist to determine techniques to aid the person who is hard of hearing on how to use the newly acquired or enhanced speech reading skills on the worksite.

The dynamics of losing one's hearing are equivalent to any significant loss. There are adjustment stages experienced that range from denial to acceptance. The length of each stage will depend on the age of onset, coping mechanisms to stress, and the availability of support systems. The underservedness identification of this group is primarily based on psychosocial components, that is, the characteristics and behaviors of the hearing impaired that appear to be prevalent with this population. The afflicted person's reaction to the hearing loss may be self-induced or based on societal attitudes. In either event, denial and withdrawal are the two elements that make rehabilitation efforts difficult both in developing outreach strategies to identify this population and finally providing service to this group.

Systems established to serve the hard of hearing have not proved to be effective. Traditional attitudes coupled with lack of sensitivity to the person's needs by the community, employer, or possibly the counselor only broaden the gap.

Both the rehabilitation counselor and the client need to become familiar with support groups such as Self-Help for the Hard of Hearing Person (SHHH) and the Association of Late-Deafened Adults (ALDA). Both groups have available materials and information which will be helpful for the professionals serving this population and for the clients. If SHHH or ALDA have local chapters, persons who are hard of hearing should be encouraged to attend meetings. Much encouragement may be needed if the client feels that his/her presence would not benefit the support group or him/herself.

DEMOGRAPHICS

Discussion of the number of people who are hard of hearing is difficult. Until very recently, the statistics listed persons who have hearing difficulty into one group--the hearing impaired. Persons who were deaf and those who were hard of hearing were combined. Jerome Schein (1991) bluntly suggests that policy-makers who do not differentiate and enumerate carefully the deaf/hard of hearing population lack adequate motivation to rehabilitate them. A more charitable statement would suggest that the rehabilitation statistical system is not sophisticated.

Data collection systems provide very consistent, valid information about the hard-of-hearing population (Hotchkiss, 1989; Reis, 1982). National studies tell us there are about 26 million persons with hearing loss in the United States (Hotchkiss, 1989; Reis, 1982; Reis, 1983). The national data base studies (National Health Interview Survey) give us a conservative and consistent frame of reference; these data can be used in a valid manner to point out the

characteristics of the hard-of-hearing population and to qualify and support policy agendas.

Hearing loss (not deafness) is one of the most prevalent chronic health conditions in America (Adams & Hardy, 1989). For persons who are hard of hearing, age 45 and above, the prevalence is greater than that of other major disabling conditions, roughly 22 million people. These data should serve to empower people who are hard of hearing (Adams & Hardy, 1989).

As can be seen in Table II-1, the incidence of hearing impairment increase dramatically with age.

Table II-3
Estimates of the Reported Prevalence of Hearing Impairment in the Population by Age Group, United States, 1987

Age Group	Number	Rate Per Thousand
Total	20,994,000	88.0
Under 18 years	1,012,000	16.0
18-44 years	5,529,000	54.1
45-64 years	6,098,000	135.6
65 years and over	8,355,000	296.8
65-74 years	4,582,000	264.7
75 years and over	3,773,000	348.0

Source: National Center for Health Statistics, Data from the National Health Survey, Series 10, Number 166, Tables 57, 62, 1988.

Significant Demographic Information

The following are specific statistics found in the research literature:

1. There is a relatively and consistently smaller deaf (as opposed to hard-of-hearing) population of around 500,000 (Brown, 1991; Hotchkiss, 1989; Schein & Delk, 1974).

2. There is an increasing trend in adult-onset hearing loss due to the aging population (the incidence and prevalence of hearing loss is age related). As the population ages, substantial and bilateral loss will become relatively more prevalent (Brown, 1991; Hotchkiss, 1989; U.S. Congress, 1986).

3. There is a decreasing trend in early-onset or congenital hearing loss due to declining numbers of births and epidemic threats; this is true for prelingual partial hearing loss as well (Gallaudet University, 1992; Northern & Downs, 1984).

4. Over 98 percent of the deaf and hard of hearing population has acquired hearing loss (Adams & Hardy, 1989; Brown, 1991; Hotchkiss, 1989; Krain, 1991; Reis, 1982; Schein & Delk, 1974).

5. Tinnitus appears to be associated with hearing loss, increases with age (Brown, 1991), and can also be associated with one's decision to use a hearing aid (one which masks the ringing in the ears);

6. Partial hearing loss is on the rise and will be even greater in the future than now due to lower mortality rates and high noise exposure in the United States (Adams & Hardy, 1989; Brown, 1991; Krain, 1991). As the population ages, hearing loss which is age related will increase.

The majority of Americans who are hard of hearing are older persons--a large number of whom have presbycusis and/or noise induced hearing losses. However, more younger persons who are hard of hearing are being found because of the "walkman" phenomenon.

Americans are living longer and are active into their eighties and beyond. These older citizens account for an increase in the prevalence of hearing loss. They, too, can benefit immensely from rehabilitation services (Corthell, 1990; Oyer, Kapur & Deal, 1976; Wood & Kyle, 1983; Glass, 1983; Green, personal communication, 1992). They may have problems hearing sounds of both low intensity and high frequencies, have poor speech discrimination, and have reduced auditory comprehension (Brown, 1991; Darbyshire, 1984; Falconer, 1986; U.S. Congress, 1986). They may also have a decline in other senses and other health problems.

Given this information, it is easy to understand how inappropriate the application of a deafness (e.g., sign language and deaf culture as a requisite) model of vocational screening and evaluation is for persons who are hard of hearing. Instead, the primary goals of rehabilitation for this population are to assist people who are hard of hearing in maintaining contact with the social and physical environments and in improving communication with these environments (Falconer, 1986; Hollander, 1982).

VOCATIONAL REHABILITATION ISSUES AND STATISTICS

Traditionally the rehabilitation literature contained occupational studies of persons who are deaf, but not of persons who are hard of hearing. Mowry (1987) indicated the vocational situation for the hard-of-hearing population is not clear. Only recently has research been conducted on the specific characteristics of the occupational status of people who are hard of hearing (Armstrong, 1991; Armstrong, 1992; Brown, 1991; Meadow-Orlans, 1985).

The Annual RSA Report for 1988 (latest available data) shows 3.3 percent of the persons rehabilitated were deaf clients and 5.3 percent were hard of hearing (RSA, 1991, 1992). These

statistics indicate an under-representation for persons who are hard of hearing as compared to other participants (in terms of their population size).

National RSA data indicates all deaf clients were coded as "severely disabled" while 60 percent of the hard-of-hearing clients were similarly coded. The statistical reports do not indicate why 40 percent of the hard of hearing were not coded severely disabled. RSA found that the majority of their hard-of-hearing applicants/clients were post-vocationally hearing-impaired. In 1988, about half of all those who were rehabilitated lost their hearing after age 19 (RSA, 1991; RSA, 1992). This data indicates that late-onset hard-of-hearing people are under-represented in the vocational rehabilitation system. Of all hard-of-hearing applicants for vocational rehabilitation services, nearly half were competitively employed at the time of application, compared to nearly 17 percent of all vocational rehabilitation applicants for services (RSA, 1991, 1992).

Homemaker Phenomena. Another interesting artifact of the vocational rehabilitation hard-of-hearing statistics is the number of persons who are hard of hearing closed as "homemakers" compared to all applicants for state vocational rehabilitation services. While 4 percent of the general vocational rehabilitation population are homemakers, nearly 20 percent of all applicants who are hard of hearing were closed in this occupation.

Restorative Devices. Restoration services were provided to nearly 90 percent of rehabilitated clients who are hard of hearing, compared to 37.3 percent of all other rehabilitated clients. The RSA data further suggests that few of these hard-of-hearing persons received any rehabilitation intervention other than hearing aid(s).

Other Services Received. Fourteen percent of the clients who are hard of hearing received training services, compared to provision of training to nearly 56 percent of all other disabled persons rehabilitated in 1988 (RSA, 1991).

The average cost per rehabilitation case (status 26) for nonhearing impaired vocational rehabilitation clients was twice that allocated to hard-of-hearing clients (hard-of-hearing [HOH] received $906 per case; deaf clients averaged $3,102). The picture is similar for duration of cases. The average total time spent in the system by persons who were hard of hearing was less than the general vocational rehabilitation population; the time spent on deaf clients was longer on the average. This disparity in service provision may be partially due to differences in severity of the disability.

Points to Consider

The following points are emphasized based upon the above referenced data base analysis and recent national analysis of people who are hard of hearing:

- The vocational rehabilitation outcome for a significant portion of the persons who are hard of hearing is not to obtain a job, but to maintain their existing job status.

- Although prosthetic devices are most likely to be prescribed by vocational rehabilitation counselors as the means for rehabilitating people who are hard of

hearing, 93 percent of HOH persons from a national (representative) study reported that hearing aids alone are not sufficient to eliminate communication problems (Armstrong, 1992).

- Hearing females stay in the labor force on the average nine years longer than females who are hard of hearing; the average age of retirement for females who are hard of hearing is age 40 (Armstrong, 1992).

- Persons who are hard of hearing are under-represented in the labor force. Compared to hearing females, 17 percent more females who are hard of hearing aged 45-54 are likely to exit the labor force. This may be due to lack of job accommodation and rehabilitation resources (Armstrong, 1991; Armstrong, 1992).

- Persons who are hard of hearing aged 45-61 are more likely to use disability benefits than hearing persons (38 percent compared to 21 percent) (Armstrong, 1992).

- When males who are hard of hearing have access to retirement benefits, they are more likely than hearing persons to retire prior to age 65 rather than remain in the labor force (Armstrong, 1992).

- People who are hard of hearing with health problems are more likely to collect disability benefits; hearing loss combined with poor health interferes with their ability to stay in the labor force (Armstrong, 1992).

- People who are hard of hearing in jobs requiring communication skills experience lower levels of income. They also tend to be in jobs that have lower education requirements (Armstrong, 1991).

- Males who are hard of hearing who are well matched for their jobs stay in the work force at the same rates as their hearing peers (Armstrong, 1992).

- Females who are hard of hearing experience higher rates of depression than their hearing counterparts (Armstrong, 1991).

FACTORS CONTRIBUTING TO BEING UNDERSERVED

Lack of Rehabilitation Collaboration. The tendency to prescribe hearing aids with no concomitant counseling is of little use to hard-of-hearing people (Armstrong, 1992; Berkowitz, 1975; Falconer, 1986; Oyer, Kapur, & Deal, 1976). Although it has been argued by some that hearing aids, when combined with appropriate informational counseling, are a great help (Mulrow et al., 1990), counselors rarely ensure that hard-of-hearing consumers receive adequate counseling (e.g., to understand ambient noise, lack of voice discrimination, to adjust to the aids, and maintain the aid). Part of the problem is lack of collaboration or a systemic approach among rehabilitative personnel (Falconer, 1986; Harvey, 1989; Lass et al., 1986). Other necessary components of the service loop for people who are hard of hearing are insufficiently

utilized (e.g., family members, audiologists, self-help and consumer groups, service agencies).

Inadequate Knowledge of Technology. Both vocational rehabilitation counselors and clients who are hard of hearing often lack knowledge about the various types of technology that are available. Nor do they understand how this technology, if appropriately used, can assist in the client's adaption to hearing loss. These technological devices can be extraordinarily important aids in the rehabilitation effort.

One of the barriers to improved use of such technology is the absence of effective marketing avenues for easy access to this technology. One could argue that these marketing avenues will not improve until there is greater awareness of the potential benefits of the technology. Markets improve with demand; therefore, well-informed service providers and clients who are hard of hearing should demand more effective use of existing technology as well as further development of even better assistive devices. Captioning of television and films is an example of a growing technology which has been responsive to consumer awareness and demand.

Communication Barriers. It is well-established in the audiological literature that the communicative ramifications of early-onset partial hearing loss are significant (Davis, 1990; Northern & Downs, 1984; Ross, 1991). The ramifications may be misunderstood particularly by counselors not trained to work with persons who are hard of hearing (Lass et. al., 1986). Partial hearing loss results in receptive communication delays and some expressive disorders, depending upon the age of onset. Even mild hearing losses can have adverse effects on a person's functioning. Due to the role hearing plays in language and speech acquisition, partial hearing loss has been known to cause lower school achievement, communicative disorders, and developmental delays (Northern & Downs, 1984).

Late-onset hearing loss results in receptive communication problems and eventually can lead to expressive difficulties. Primary rehabilitation needs are aural-oral rehabilitation and appropriate counseling, including referrals to self-help groups and agencies that provide assistance in getting low-cost assistive technology and/or hearing aids. Receptive communication barriers crosscut the school, work, family, and social environments. They may lead to secondary rehabilitation needs in the areas of health care, work place modification and accommodation, and job re-training. Self-advocacy/assertiveness training, education, and family counseling may be indicated. Lack of community resources leads to further social ramifications such as early retirement, underemployment, and higher rates of mental illness (Armstrong, 1991; Armstrong, 1992; Brown, 1991; Mowry, 1987; Pollard, 1987; Wood & Kyle, 1983).

Secondary Health Problems. There is specific evidence in the research and literature from numerous fields that hearing loss creates secondary health problems (Armstrong, 1992; Berkowitz, 1975; Brown 1991; Falconer, 1986), that in turn affect job performance and one's ability to stay in the work force. Partial hearing loss is significantly associated with higher scores on sickness impact profiles (Thomas, 1984). Adult-onset hearing loss is an important functional determinant of health, social, and family life (Armstrong, 1991; Darbyshire, 1984; Bess, Lichtenstein, Logan, Burger, & Nelson, 1989; Bess, Lichtenstein, & Logan, 1991).

Physical Plant. Section 504 of the Rehabilitation Act of 1973 and the recently enacted

Americans With Disabilities Act require physical access to public buildings, services, and programs. These laws will require that vocational rehabilitation offices or other agencies covered under these laws make compliance efforts beyond Telephone Devices for the Deaf (TDDs) and telephone amplifiers. Important to the accommodation of clients who are hard of hearing are (a) interview/counseling settings free from background noise and distractions, (b) movable furniture which will enable direct line of vision, and (c) maximum use of good lighting. The vocational rehabilitation facility should provides assistive listening devices such as induction loop systems, infrared units, or FM units to assist people who are hard of hearing in their communication. These devices are particularly helpful in many employment setting (e.g., staff meetings, in-service training).

SUMMARY AND CONCLUSIONS

The problem of underservedness crosscuts a number of areas. There is an extreme lack of communication and collaboration across disciplines, including lack of outreach to persons who are in direct contact with persons who are hard of hearing. Persons who are hard of hearing do not enter the system in the same manner as deaf consumers. Public schools, post-secondary settings, physicians, geriatric settings, audiology and speech clinics, mental health settings, and consumer organizations are vital in the effort to integrate people who are hard of hearing into the mainstream of society (Darbyshire, 1984; Ross, 1991; Castle, personal communication, 1992).

If a person who is hard of hearing is found eligible, then the issue of understanding the range of rehabilitation services that are needed beyond the hearing aid come into play (Trychin, personal communication, 1992). Current practices in purchase of restorative devices and "homemaker" closures need to be addressed. More emphasis on addressing the value and uses of assistive technology in the work place is called for. Workers who are hard of hearing in high communication job settings urgently need appropriate counseling and information about assistive technology to maintain appropriate employment.

Chapter III

POLICY AND PROCEDURE

This chapter will discuss the current policy and procedures in vocational rehabilitation as they impact persons who are hard of hearing. At the federal level will be discussed two statutory compliance issues: order of selection and accessibility. Also discussed are priorities in research and training, the impact of adding a position that attends to issue of concern to persons who are hard of hearing, and oversights of state agencies. At the state level, the chapter will cover cooperative agreements, consumer empowerment, in-service training, order of selection, and program evaluation.

FEDERAL POLICY AND PROCEDURE

Statutory Compliance Issues

Order of Selection for Services. If an agency determines that it is unable to serve all eligible individuals who apply, it must, under The Vocational Rehabilitation Act of 1973, as amended in 1992[1], assure that those individuals with the most severe disabilities are selected for service before individuals with less severe disabilities. While new regulations have not been developed for the amendments, current regulations for order of selection purposes (Rehabilitation Services Manual, Chapter 2501.08- Order of Selection for Services Guidance- 1992), require that the determination of severe handicap [disability] for an individual with impairments is to be made within the context of the statutory and regulatory definition of "individual with severe handicaps [disabilities]. As stated in the 1992 amendments:

> (15) (A) . . . [For the purpose of Title I, the basic state grants program] the term "individual with a severe disability" means an individual with a disability . . .
>
> (i) who has a severe physical or mental impairment which seriously limits one or more functional capacities (such as mobility, **communication**, self-care, self-direction, **interpersonal skills, work tolerance**, or work skills) in terms of an employment;
>
> (ii) whose vocational rehabilitation can be expected to require multiple vocational rehabilitation services over an extended period of time; and
>
> (iii) who has one or more physical or mental disabilities resulting from amputation, arthritis, autism, blindness, burn injury, cancer, cerebral palsy, cystic fibrosis, **deafness**, head injury, heart disease, hemiplegia, hemophilia, respiratory

[1]Bracketed information throughout this chapter indicates changes in language introduced in amendments or to clarify statements for reader. Bold emphasis added throughout definition to emphasize functional areas that apply to hard of hearing.

> or pulmonary dysfunction, mental retardation, mental illness, multiple sclerosis, muscular dystrophy, musculo-skeletal disorders, neurological disorders (including stroke and epilepsy), paraplegia, quadriplegia and other spinal cord conditions, sickle-cell anemia, specific learning disabilities, end-stage renal disease, **or another disability or combination of disabilities determined on the basis of an assessment for determining eligibility and vocational rehabilitation needs described in subparagraphs (A) and (C) of paragraph (22) to cause comparable substantial functional limitation.**
>
> (15) (B) For purpose of title VII [Independent Living], the term "individual with a severe disability" means an individual with a severe physical or mental impairment whose ability to function independently in the family or community or whose ability to obtain, maintain, or advance in employment is substantially limited and for whom the delivery of independent living services will improve the ability to function, continue functioning, or move towards functioning independently in the family or community or to continue to employment, respectively.
>
> (15) (C) For purposes of section 13 [Community Based Programs] and title II [Research], the term "individual with a severe disability" includes an individual described in subparagraph (A) or (B).

Current RSA policy guidance, RSM Chapter G2501.08, page 19, further clarifies that it is this

> combination of functional limitations and the need for multiple services over an extended period of time that determine severity of handicap [disability]. Thus, determining severity of handicap [disability] for order of selection purposes, differs from the routine determination of severe disability for RSA-911 reporting purposes.

This is an important distinction since in many instances persons who are hard of hearing are automatically excluded from services. Often an order of selection is imposed because the RSA-911 definition for "severely disabled hard of hearing" is incorrectly applied instead of the statutory definition for "individuals with severe handicaps [disabilities]."

When one examines the definition of individual with severe physical disabilities, it becomes apparent that many persons who are hard of hearing would not meet the RSA-911 coding definition audiologically. However, these same individuals might well be "severely impaired" functionally in their employment situation and thus meet the definition for the priority population for receipt of services under an order of selection. The opposite may also be true--a person may meet the RSA-911 coding definition audiologically but have a mild functional impairment. For example, an individual who has been hard of hearing over a long period of time, who has already made the necessary job task and job site modifications, who is appropriately coping, and who needs only a replacement hearing aid would not meet the definition and should not be served in an order of selection situation. On the other hand, an individual, perhaps with a less severe hearing loss, who is in need of counseling for stress and coping skills, who needs job task/site assessment and modification, and who needs assistive listening device(s), in addition to a hearing aid, may well be considered an "individual with

severe handicaps." This latter individual should be in the priority group under an order of selection for services.

Like all other aspects of the vocational rehabilitation program, one must look at the individual and his or her individual functional limitations, employment impairment, and scope of service needs to determine eligibility and severity of handicap. It is not possible to make such determinations based on audiometric diagnosis alone.

Accessibility. Section 504 of the Rehabilitation Act of 1973, as amended, and the Americans With Disabilities Act both require communication and technological accessibility in all aspects of vocational rehabilitation programs and services. Compliance, as it affects clients and staff who are hard of hearing, relates to both staffing and physical plant considerations.

Staff. State vocational rehabilitation agencies should employ counselors who have the specialized knowledge and communication skills needed to effectively assess and serve individuals who are hard of hearing. In many instances, clients who are hard of hearing are viewed as "easy hearing aid cases," and referrals are distributed among generalist counselors. Because the hard-of-hearing person's speech is readily understood, it is erroneously assumed that the person who is hard of hearing will understand the counselor without any special communication considerations.

In other instances, clients who are hard of hearing are assigned to the office "deaf specialist" counselor, who is assumed to understand the needs and service options for all persons who are hearing impaired. "Deaf specialist" counselors are (or should become) highly skilled in deafness rehabilitation and communication modalities associated with deafness. Unfortunately, many specialists have little understanding of the very different psychosocial, communication, and technological needs of their clients who are hard of hearing.

Staff (from receptionist to counselors) need training in how to communicate with persons who are hard of hearing. Poor communication habits such as covering the mouth, failure to face the client, smoking, and beards and moustaches covering the lips need to be eliminated. If not, the communication problems are compounded as persons who are hard of hearing rely heavily upon visual and auditory clues. A counselor's speech impairment or impediment will compound the communication problems. Some clients who are hard of hearing may require reassignment to counselors whose speech they can readily understand.

Physical Plant. Many vocational rehabilitation agencies have made compliance efforts in the form of TDDs and telephone amplifiers. Seldom provided, but equally important to the accommodation of clients and staff who are hard of hearing, are interview/counseling rooms free from background noise and distractions. Such rooms ideally are equipped with moveable furniture enabling direct line of vision and maximum use of lighting. Even rarer are facilities which provide assistive listening devices such as loop systems or FM units to assist clients and staff who are hard of hearing in their communication. Offices that serve persons who are hard of hearing should be equipped with one or more assistive listening devices and staff trained in its use.

Priorities in Research and Training

The federal government in 1992 recognized the need for research and training in order to enhance the scope and quality of services for individuals who are hard of hearing. Priorities were established and the request for proposal (RFP) was announced. The proposal called for funding a three-year contract to conduct a national assessment of the rehabilitation needs of individuals who are hard of hearing.

A one-year grant was awarded to the Arkansas Continuing Education program to develop a curriculum to train vocational rehabilitation counselors who serve clients who are hard of hearing. The grant called for training personnel in all regions of the country.

An RFP for a five-year hearing research center to conduct basic and applied hearing research activities was promulgated. In 1992, a $6,000,000 grant was awarded to Oregon Health Sciences University in Portland to support a hearing research center there. This Center is under the direction of Dr. Jack Vernon and will conduct basic and applied research over a five-year period, focusing on the rehabilitation of individuals with significant hearing loss.

The service needs of persons who are hard of hearing was selected as one of the areas to be discussed in this IRI document on underserved vocational rehabilitation populations. It is hoped that this is an indication that the unmet needs of persons who are hard of hearing are beginning to be recognized.

As a result of the above projects, research and training needs will be identified and prioritized that will further respond to the full scope of needs of clients who are hard of hearing. The mandates of the Rehabilitation Act reauthorization, which places special emphasis on underserved populations and on the use of rehabilitation technology in employment settings, should keep hard of hearing issues at the forefront of research and training.

RSA Organizational Structure and Policy Development

Within the RSA there has long been an Office of Deafness and Communication Disorders (now Deafness and Communicative Disorders Branch) that initially attended to the needs of individuals who were deaf. In recent years it was recognized that the problems and needs of individuals who are hard of hearing are different from those encountered by persons with early-onset deafness. In response, the commissioner added a staff person whose responsibility is to attend to the interests of persons who are hard of hearing. The addition of this position has made a tremendous impact on awareness of issues regarding rehabilitation of persons who are hard of hearing. Policy, research, and training needs are now identified on an ongoing basis.

In addition to a specialized staff person, there is an increasing mandate and need to involve consumers and advocacy groups at the federal policy level. Representatives of groups such as Self Help for Hard of Hearing People, Inc., and the Association for Late Deafened Adults, in addition to grass roots consumers, can (a) enhance and lend credibility to policy changes, (b) advocate for research and training priorities and the necessary funding, and (c) help RSA interpret laws and develop policy as it relates to individuals who are hard of hearing. In short, these consumers can greatly assist to increase awareness of and sensitivity to their

disability among federal planners and policy makers.

Oversight of State Agencies

The RSA Central Office has identified persons who are hard of hearing as a separate underserved population group that needs unique service intervention. RSA has demonstrated a strong commitment to meeting these needs. They must now translate this commitment to the state level. To accomplish this goal, training must be developed and delivered to RSA regional office staff to increase their awareness of this disability and to gain a like commitment. Armed with adequate knowledge, regional office staff will motivate states to provide appropriate services to clients who are hard of hearing. The regional office staff can assure improved services to persons who are hard of hearing by:

1. Monitoring and review of State Plans and in-service staff development and training plans;

2. Regular case reviews and 911 data monitoring;

3. Assuring that enhanced services are provided to each state's population of individuals who are hard of hearing; and

4. Giving special attention in case reviews of states where an order of selection for services is in effect. Attention should be given to whether or not the definition of "individuals with severe handicaps" is being correctly applied to clients who are hard of hearing.

STATE POLICY AND PROCEDURE

Cooperative Agreements

Historically, there has been an excellent cooperative effort between consumer groups representing persons who are deaf and the Rehabilitation Services Administration. This has resulted in an increased awareness of services which can be provided by vocational rehabilitation on the part of the consumers who are deaf. State vocational rehabilitation agencies have also developed an increased sensitivity to the rehabilitation needs of persons who are deaf. Over the years, this interactive cooperative effort has resulted in the writing of several "Model State Plans for Service to Persons Who Are Deaf." These plans have identified essential guidelines and standards for staffing, training, and on-going development of rehabilitation initiatives to more effectively serve that population group. Many state agencies have aggressively implemented these standards.

A similar cooperative effort is also needed for persons who are hard of hearing. In 1987, a joint statement of principles of cooperation was drafted by Self Help for Hard of Hearing, Inc. (SHHH), the Rehabilitation Services Administration, National Institute on Disability and Rehabilitative Research, and the Council of State Administrators of Vocational Rehabilitation. (See Appendix C). This agreement was intended to stimulate the membership population of

SHHH to become knowledgeable about vocational rehabilitation services to which they are entitled. It was hoped the agreement would establish and foster a close working relationship between the consumer group and the state program of vocational rehabilitation. In the agreement, state agencies were encouraged to examine their commitment to serve persons who are hard of hearing.

Relatively little progress has been made in the implementation of the initiatives suggested in this original cooperative agreement. Further encouragement is needed to develop state/local level cooperative agreements between state rehabilitation agencies and state chapters of persons who are hard of hearing. Greater effort is needed to foster development of model programs in which the partnership can result in expanded and improved services to this presently underserved population.

Consumer Empowerment. Consistent with the objective of establishing cooperative agreements is the need to actively seek out representation of persons who are hard of hearing to serve on state vocational rehabilitation Consumer Advisory Councils. Parenthetically, the sometimes complex reality of providing necessary communication accessibility, which will enable a person who is hard of hearing to fully participate in an Advisory Council meeting, can increase the awareness of the implications of having a hearing loss. Knowledgeable consumer input can provide the state agency invaluable information on such issues as referral sources, adaptive techniques, and technology used by persons who are hard of hearing. Input regarding rehabilitation approaches that will enhance the employment and independent living opportunities for this population should be sought.

In-Service Training. Ignorance is the predecessor to indifference, and indifference is frequently at the core of why persons are underserved. Current caseload statistics of persons who are hard of hearing reflect the underserved nature of this population. This often results in a lower priority assignment on the in-service training calendar of the state agency for subjects related to persons who are hard of hearing. Any state agency which will earnestly examine its commitment to better serve persons who are hard of hearing will quickly appreciate the need to also examine the associated knowledge base of counselors who deliver these services to persons who are hard of hearing. Conscious, deliberate effort must be made to incorporate into the State Plan for Human Resource Development appropriate in-service training focused on the needs of persons who are hard of hearing.

Order of Selection

States that are contemplating or currently have order of selection policy written should be aware that a person who is hard of hearing may be severely impaired by two or more disabilities or functional impairments that seriously limit one or more functional capacities in terms of an employment outcome.

The service to persons who are hard of hearing is directly related to how the state vocational rehabilitation agency determines the impairment aspect in the eligibility process. If the common practice is to determine severity of impairment on the basis of audiometric diagnosis alone, then an even greater probability exists for underservedness when an order of selection policy is imposed. It is essential that the determination process involves a more detailed and

careful assessment of the functional limitations caused by the hearing loss. The extent to which hearing loss may impact communication, inter-personal skills, and employment options requires sensitive and knowledgeable counseling. Such assessment is likely to identify functional limits in greater detail than an audiometric score alone can describe. Using a functional assessment approach details the experiential effect of hearing loss upon the individual. This approach will lead to a greater number of persons who are hard of hearing meeting the criteria for severity of impairment used in the order of selection process.

Program Evaluation. The state agency program of quality control should initiate a program evaluation mechanism specifically targeted on underserved populations. Evaluation formats are needed which are designed to go beyond issues of compliance with regulations. For persons who are hard of hearing, evaluative judgment is necessary regarding how well functional assessment is being done. It should address what specific services are being provided to address identified limitations. Of particular significance, with the initiation of the American with Disabilities Act, is an evaluation of the use of assistive devices and accommodation technology.

Quality programming for persons who are hard of hearing will go beyond the provision of hearing aids alone. Quality programming will reflect an awareness of the complexity of the disability and should illustrate this awareness in the nature of services provided. Again, a conscious effort must be made in the development of program evaluation strategies which will effectively track how well the state agency is meeting the needs of this traditionally underserved population.

Chapter IV

BEST PRACTICES: PARTNERSHIPS WITH PERSONS WHO ARE HARD OF HEARING

During 1989, federal rehabilitation agencies in 50 states across the country closed over 13,000 clients who were hard of hearing as rehabilitated. The most common rehabilitation service provided was a hearing aid. Persons who are hard of hearing need more than an appliance. They will often need to use assistive technology such as listening devices and telephone assistive devices. During rehabilitation many will need new coping skills, on-site work environment evaluations for communication barriers, appropriate follow-up services, and vocational related services for the home. These are, and should be, our challenges as rehabilitation counselors to persons who are hard of hearing.

There are five major components to this chapter that are based on the vocational rehabilitation service model. These components are (a) case finding, (b) interview accessibility and approaches, (c) eligibility considerations, (d) points to consider in the individual written rehabilitation program development and service delivery, and (e) placement and follow up. Several interview guides and check sheets are provided for the readers' adaptation.

The vocational rehabilitation counselor new to working with persons who are hard of hearing needs to have a sensitivity to and an awareness of the vocational ramifications of a hearing loss. Counselors who are effective in working with clients who are hard of hearing will need to apply different knowledges, sensitivities, and skills to their usual case practices. Serving clients who are hard of hearing requires a continuous focus by the counselor on the clients' communication limitations. There are "invisible" effects associated with a hearing loss which can have significant vocational implementations for the client. This is especially significant in vocational placement and follow up.

IMPORTANCE OF CASE FINDING

In the United States, there are thousands of adults in the world of work who are faced with a communication disability caused by a hearing loss. A hearing loss can (a) occur at any age, (b) range from mild to profound degree of loss, and (c) have sudden onset or be slowly progressive. It is a hidden disability in which individuals often refrain from seeking assistance with the tendency to "put off" getting help until circumstances, friends, family, or employers strongly encourage them to face the reality that help is needed.

Some people acquire a hearing loss at birth or shortly thereafter. Those individuals, with

early-onset hearing loss, rarely know what it is like to have "normal hearing." They are not aware of the full impact of the hearing loss.

Hearing loss most frequently is gradual--often of several years' duration. Although these individuals may be aware of a problem, they rationalize that "everyone has problems hearing now and then." In fact, friends, associates, family members, and employers may be more attuned to the functional impact of the hearing loss than the individual. When a person is ready to seek help, most likely he/she will not be aware of services and devices that can help. If the person is aware of a vocational rehabilitation program, often the perception is that rehabilitation is a program for persons in wheelchairs, persons who use a cane, or persons who can't speak and use sign language.

People who have early-onset moderate or even mild hearing loss may have difficulty in obtaining their first job. Although the hearing loss is often a significant factor in not getting employment, these people are unable to qualify for Social Security benefits such as Supplemental Security Income on the basis of their hearing loss. This indeed, makes it extremely difficult for them to meet living expenses compared to persons who are deaf and others who are considered severely disabled who can at least draw Social Security.

Most persons who are hard of hearing were referred to vocational rehabilitation because they do not have the financial resources for a hearing aid. This is most unfortunate, as it implies that referral providers will not refer a person to vocational rehabilitation if she or he can afford the purchase of a hearing aid.

It is suggested that vocational rehabilitation counselors contact the following in their outreach and case finding activities:

- Students who are hard of hearing and who do not require special education services; school contacts should include not only the special education department but counselors and school nurses.

- Otologists, audiologists, speech and hearing clinics, and hearing aid dealers; it can be explained to them that many persons with hearing loss need services beyond the fitting of a hearing aid.

- Develop relationships with support groups that are serving persons who are hard of hearing.

- Civic clubs, state and private social service agencies, Chambers of Commerce, employers in the community; presentations to these organizations should stress awareness.

- Local community, state, and private college special needs counselors who may have students who are hard of hearing who are in need of vocational rehabilitation services.

- Current clients who can be encouraged to refer friends, relatives, who have hearing problems.

- Centers for Independent Living; explain to the Center personnel the services the agency may provide to persons with hearing loss.

Every state vocational rehabilitation agency should have a special outreach brochure that focuses on possible services to persons who are hard of hearing. Providing vocational rehabilitation services to persons who are hard of hearing can be a rewarding and satisfying experience for the counselor and the client. There is need to make the vocational rehabilitation process available to more persons who are hard of hearing and to provide comprehensive service.

INTERVIEW ACCESSIBILITY AND APPROACHES

A letter should be sent to persons referred for service who are hard of hearing indicating the time and place for the initial interview. That appointment letter should also request that the individual:

1. Bring his/her hearing aid and batteries.

2. Bring any assistive listening device used which will aid in communication. (e.g., Pocket Talker, FM System, etc.). Counselors should be aware that under the provisions of the Americans with Disabilities Act, government entities must provide auxiliary aids and services for individuals who request or need them. (See Section §36.303 of the Federal Register in Appendix D for listing of qualified auxiliary aids).

3. Indicate whether or not an oral interpreter for speechreading or a sign language interpreter is useful. If so, one should be available for the first interview.

For the interview, it is especially important for the counselor to establish the most favorable communication environment possible for the client. To do this, the office should be as quiet as possible, even if this may mean moving to another place in the office such as a conference room for the interview. In addition to creating a quiet environment, the counselor can do the following to assist the client:

1. Move from behind the desk and sit next to the client so they are facing one another.

2. Make certain the client is not bothered by sunlight from a window. Persons who are hard of hearing needs to see the speaker's face without distractions or glare.

3. When speaking, the counselor should not chew gum, smoke, or cover his/her mouth; he/she should speak at a normal pace, or, if a fast talker, speak a little slower.

4. Inquire if he/she is speaking loud enough; the counselor could also speak too loudly, so the client should be asked what is comfortable.

5. If the client is having problems understanding what is being said, try rewording as some words are easier to speechread than others. Keep sentences simple but be sensitive that it may sound as though he/she is talking down to the individual.

6. Be patient, be encouraging, use positive facial expressions, rather than negative facial expressions.

7. Be aware that many people with hearing problems have become adept head nodders. They indicate understanding rather than frequently asking that a statement be repeated. Check by asking questions that can not be answered yes or no or with a head nod.

8. Some persons who are hard of hearing have speech articulation and voice fluctuation problems. Some individuals, who never heard speech clearly have the most difficulty with speech. However, most people who are hard of hearing have good clarity in their speech since they had normal hearing at one time. The more the counselor listens to a person who is hard of hearing, the easier it will be to understand him/her. Focus on the total context rather than individual words.

9. If there is an important word the counselor doesn't understand, such as an address, have the person write it, don't guess!

10. When giving appointment times, dates, places, always give it in writing to the client.

11. When making appointments for the client, make sure that the doctor's office, psychologist, etc., is aware that the individual is hard of hearing.

12. Always treat the client who is hard of hearing with respect and help build confidence in his/her abilities and in yourself as a rehabilitation counselor.

13. It is also good to summarize in the case file the changes made to assist the client in communication for future meetings.

14. Make sure appropriate follow-up letters are sent.

When first meeting a person who is hard of hearing, the false assumption is often made that the person has minimal vocationally related problems. This impression is especially strong if the person has good speech, but it is often a false assumption. An in-depth interview about the client's impairments and functional problems can identify a multitude of vocationally related issues. These, in turn, can be used to document a substantial impairment to employment.

Table IV-1 suggests questions that may assist the counselor in understanding and documenting the disability and its impact on the client.

Table IV-1
Suggested Initial Interview Questions

Functional Assessment

1. Were you born with your hearing loss?
2. When did you find out you were hard of hearing or have a hearing problem?
3. Did you have normal hearing at one time?
4. Do you hear low (deep) or high pitched sounds the best?
5. How well can you use a telephone? Can you hear the phone ring?
6. Do you have a flashing light? A TT or TDD?
7. Do you like the television loud to the point it bothers others?
8. What kinds of communication problems do you experience with your immediate family?
9. What is your most difficult listening situation?
10. What is your best listening situation?

Hearing Aids (if applicable)

1. When did you get your first hearing aid?
2. How old is your present hearing aid?
3. Have you ever worn two hearing aids at the same time?
4. How has the hearing aid helped you?
5. What problems have you had with a hearing aid? Is your present aid satisfactory? Why not?
6. Do you have a telephone switch on your hearing aid?

Assistive Listening Devices

1. Have you used an FM System?
2. Have you used a Loop System?
3. Have you used an amplified phone? Loud Bell?
4. Have you used an Infrared System?
5. Have you used a pocket amplifier or TV listening device component?
6. Have you used a TV decoder?

Medical

1. When was the last time you saw an ear doctor?
2. When did you last have your hearing tested and where was the testing done?
3. Have you had surgery to correct your hearing loss?
4. Are you often tired and do you have frequent headaches?

Table VI-1
Suggested Initial Interview Questions (continued)

Visual Screening

1. Do you experience any problems with your vision?
2. Do you usually wear glasses or contact lenses?
3. How long have you had your present glasses (contacts)?
4. Do you have problems reading the phone book or newspaper?
5. Do some things seem blurry to you?
6. Do you have any eye "pain" or eye strain?
7. When did you last see an eye doctor?
8. Does bright light bother you?
9. Do you have more vision problems at night?
10. Does anyone in your family have Usher's Syndrome or deafness with tunnel vision?
11. Have you been checked for cataracts or glaucoma (if over 40 years old)?

Vocational

1. Does your hearing loss cause problems on your present or last job?
2. Do you have problems understanding your supervisor?
3. Do you have problems understanding your co-workers?
4. Do you miss deadlines or instructions?
5. Do you find yourself withdrawing from your co-workers?
6. What problems do you experience in group meetings?
7. Do you have any problems using the telephone as part of your responsibilities?
8. Do you find it difficult to ask questions?
9. Do you understand people better when they face you?
10. Do you find people to be rude if you ask them to repeat?
11. Do you depend a lot on speechreading (lip reading)?
12. Doe your co-workers and boss know you have a hearing problem?
13. Do you feel your co-workers and supervisors understand your hearing problem?
14. Do you try to "hide" your hearing loss at work?
15. What causes stress at work?
16. What help do you feel you need in order to be vocationally successful?
17. What problems are you having in your daily life, in the home, which affect your work and are related to your hearing loss?
16. Are you really tired at the end of a work day?

Speech and Language (optional depending on whether there is a serious speech clarity problem)

1. Have you had speech therapy or speechreading lessons?
2. How do you feel about your speech?
3. Do you feel you need speech therapy?

Table IV-1
Suggested Initial Interview Questions (continued)

Sign Language (Optional)

1. How did you learn sign language?
2. How often do you use sign language?
3. Do you need a sign language class?

Psychological/Social Issues

1. Do you try to hide your hearing loss at times?
2. Have you had any training on how to adjust to your hearing loss?
3. What problems are you having in your daily life, in your home life, which you associate with your hearing loss?
4. Do you avoid people because of your hearing loss?
5. Does your hearing loss keep you from having friends?
6. How do you feel about your social life?

ELIGIBILITY DETERMINATION

Medical Examination

The major purpose of a general medical examination of the person who is hard of hearing is to assist the counselor in identifying other physical conditions that could have vocational implications. As such conditions are identified, appropriate medical specialists' exams should be authorized. There have been instances where a general medical exam may indicate mental retardation since the client's mannerism of responses and speech characteristics could mistakenly be interpreted as characteristics of mental retardation. Diagnosis of mental retardation should be made only by a qualified psychologist (preferably with experience and training in testing persons who are hard of hearing) using appropriate performance assessment tools of evaluation.

Persons who have a hearing loss should be evaluated by an otologist, or otolaryngologist, who specializes in diagnosing and treating diseases of the ear. The client should also be seen by an audiologist who has a minimum of a master's degree in audiology and is trained in identification, assessment, and rehabilitation of hearing loss. In many medical settings, which specialize in treating hearing disorders, the otologist/otolaryngologist and the audiologist work together as a team providing comprehensive services. The medical report from the otologist/otolaryngologist should answer the questions listed in Table IV-2.

The counselor should provide the otologist and/or audiologist a brief client vocational history and possible vocational goal so they can address the counselor's vocational questions. In addition, the history should indicate the questions the counselor wants answered.

Table IV-2
Questions for Specialists

Otologist/Otolaryngologist

1. What type of hearing loss does the client have (sensorineural, conductive, mixed)?
2. Is the hearing loss bilateral/unilateral?
3. What was the age of onset of hearing loss?
4. Is the hearing loss progressive, stable, or fluctuating?
5. Are there indications of physiological problems such as tinnitus, vertigo, scarred ear drums?
6. What are (if any) the possible correction procedures for the hearing loss?
7. Is surgery more appropriate than fitting of hearing aids? If so, what is the expected outcome?
8. Are there any vocational (or other) situations from a medical perspective to be avoided?

Audiologist

1. What is the degree, measurement of hearing loss, pure tone and bone conduction, and average loss in speech range?
2. What are the functional aspects of hearing loss...what sounds will be difficult for the client to understand?
3. What vocational environments would be difficult for the client in terms of speech discrimination and sound awareness?
4. Are there modifications to vocational environment that would assist the client in communication (reasonable accommodations)?
5. What are the possible effects of noisy environments on the client's residual hearing.
6. What is the condition of the client's present hearing aid(s)? Should a different hearing aid be considered?
7. What assistive listening devices would be beneficial for the client, especially in the vocational environment?
8. What is the individual's speech discrimination ability in noisy and quiet environments, and what is the degree of expected improvement with amplification.
9. Are additional services recommended?

Audiometric charts and otological reports do not fully represent the impact of the disability of hearing impairment on an individual. There could be persons who have similar audiograms but have significantly different functional skills. This is why an in-depth interview by the counselor about the client's hearing loss is so important as part of the diagnostic determination of vocational handicaps.

Visual Examination

For clients with any level of hearing loss, counselors should screen for any vision problems. They should especially be aware of a hereditary condition called Usher's Syndrome, which includes both hearing loss and visual fields loss leading to tunnel vision. Age is often a critical factor in vision disorders. Counselors should not always depend on the general medical exam to identify vision disorders but should specifically question the client and authorize a specialist's exam if visual problems are suspected.

Hearing Loss as a Secondary Disability

The percentage of clients with multiple disabilities, including hearing loss, is increasing. These individuals represent a greater challenge to rehabilitation counselors. For those clients who are limited by visual, cognitive, dexterity, autism, or other sensory/physiological disabilities, greater emphasis must be placed on the diagnostic process including the possible use of an extended evaluation program to determine vocational rehabilitation potential. The hearing loss has an even greater impact on limitations for those clients who have multiple disabilities.

Infrequently, a client may be in need of mental health services. This calls for a professional judgment with appropriate referrals for diagnostic and treatment. Counselors should assist the client in making sure mental health services are made accessible which could include the auxiliary services listed in the American with Disabilities Act (see Appendix D).

Hearing Loss and Substantial Impediment to Employment

Early Hearing Loss Signs. When documenting a substantial impediment to employment, the counselor has to consider the client's:

1. History and vocational problems in previous work experiences;

2. Functional limitations in response to environmental sounds and discrimination of spoken words; and

3. Occupational goal.

Often, the persons around the individual who is hard of hearing recognize a problem before the person with the hearing impairment is willing to face the issue. A person who is experiencing a hearing loss may exhibit a combination of the following:

1. Problems hearing instructions;

2. Missing deadlines due to misunderstandings;

3. Withdrawal from other employees because communication is stressful;

4. Avoidance of situations requiring communication and is considered a "cold blooded," or "reserved" person;

5. Monopolizing conversations in an attempt to avoid having to listen to others and where questions are asked that are not heard;

6. Avoidance of situations that require the use of a phone;

7. Avoidance of group meetings (more than normal);

8. Discomfort in noisy environments where hearing aids are often a hindrance;

9. A belief that most people mumble;

10. Indications of understanding verbal communications, but really doesn't (bluffing);

11. Innovative use of reasons to get others to repeat what another person said;

12. Better understanding when facing the speaker because of the use of speechreading;

13. Leaving jobs for no obvious reasons when people are speaking;

14. Turning down promotions (poor self-esteem, anxiety of new responsibilities, new job requires more verbal communication);

15. Talking significantly louder (or softer) than others; and

16. Reluctance to ask questions because they may have been answered before and does not want to appear stupid.

As indicated above, there are a multitude of ways that a hearing loss impinges upon a person's ability to perform vocationally. In addition, a hearing loss causes stress in ali aspects of a person's life to the point of causing fatigue, anxiety, loss of acceptance by others, loss of self-confidence, stress-related health problems, marital problems, and social problems.

Environmental Sounds. A client with a high (or low) frequency loss will not respond to corresponding high (or low) frequency sounds. For example, the person with a high frequency hearing loss may not hear the bell that sounds when a customer enters a place of business or hear the delivery truck when it backs up to the loading dock. The same person could hear the phone ring when standing next to the phone but will not hear it when ten feet away. The absence of the ability to respond to key environmental sounds in a person's place of employment could easily constitute a substantial vocational handicap.

Word Discrimination. A client's functional limitation can also be documented on the ability to understand and to discriminate speech. In addition to the degree of hearing loss, there are numerous other factors which determine a hard of hearing person's speech discrimination ability. Some of these are listed in Table IV-3.

Table IV-3
Factors Affecting Speech Discrimination

The Speaker	The Environment
Voice intensity	Noise
Voice projection	Lighting
Rate of speech	Distance from sound
Clarity of speech	Room acoustics
Facial expression	Distractions
Body language	Ventilation
Foreign accent	Seating arrangement
Position of listener	Failure to use visual cues
Beard, moustache	Failure to provide assistive listening devices
Mannerisms	
Oral movements (easy to speechread)	

Speech discrimination scores provided by audiologists are completed in an audiological booth. The scores generally represent how well the person can discriminate individual words (in a controlled environment). As indicated above, there is a variety of factors that determine speech discrimination ability in each communication situation.

A rehabilitation counselor needs to understand that a person who is hard of hearing may do well in communicating in one work area but have major communication difficulties in another. Therefore, when justifying a substantial impediment to employment the ability to hear speech in the work environment must be considered. The combination of an inability to respond to key sounds in a person's work environment and/or the variance of ability to discriminate speech in the work environment are key limitations that a counselor can address when writing an eligibility statement.

INDIVIDUALIZED WRITTEN REHABILITATION PROGRAM AND SERVICE DELIVERY CONSIDERATIONS

The key to a good plan is to identify the services needed by the client. For clients who are hard of hearing, the plan should focus on restoration services, communication skills and devices, vocational selection and training, counseling and guidance/ coping skills, and ancillary vocational services.

Restoration Services

Service providers who are trained to work with persons with hearing and communication disorders include:

Otologist or Otolaryngologist. A medical doctor with specialized training in diagnosing and treating diseases of the ear. Services may be:

1. Medical treatment for infection, growth in the ear, and other medical problems;
2. Surgery to correct conductive hearing problems such as scarred ear drums and middle ear surgery;
3. Cochlear implants for sensorineural hearing problems; and
4. Correction of vestibular disorders.

Audiologist. A person trained in identification, assessment, and rehabilitation of hearing loss who holds an advanced degree in audiology. Services include:

1. Audiometric screening and testing. May also help pinpoint the site of the lesion and do other special testing;
2. Speech discrimination testing and scores;
3. Hearing aid evaluations;
4. Auditory training and adjustment counseling;
5. Marketing of hearing aids (optional) and fitting ear molds;
6. Marketing of assistive listening devices (optional);
7. Repair of hearing aids (send to factory); and
8. Provide loaner aids.

Speech and Language Pathologist. This individual is trained in identification, assessment, and rehabilitation of persons who have speech and language disorders. Services may encompass:

1. Speech and language evaluation;
2. Speech therapy for articulation disorders;
3. Therapy for voice disorders;
4. Therapy for language processing disorders;
5. Speech communication assistive devices; and
6. Speechreading training.

Hearing Aid Dispenser (Dealer). These entrepreneurs market (sell) hearing aids. Many states require a hearing aid dealer to acquire a license. Their services may include:

1. Selection and fitting of hearing aids and ear molds;
2. Repair services;
3. Follow-up services; and
4. Assistive listening devices (optional).

Amplification Devices

Hearing Aids. A majority of clients who are hard of hearing are referred to vocational rehabilitation agencies for the purpose of getting a hearing aid(s). The following statements will help rehabilitation counselors to identify the vocational benefits and problems associated with hearing aids:

1. A fitting of a hearing aid **does not** bring normal hearing to the client. However, in individual cases, hearing aids can increase speech discrimination scores and sound awareness.

2. Hearing aids do make sounds louder. Newer models of hearing aids can be adjusted to individually meet the needs of the client, based on the audiogram.

3. New hearing aid users have a greater adjustment and rejection of aid than experienced hearing aid users.

4. The behind-the-ear aid and body aid have a better reliability record and less frequent need for repair than in-the-ear instruments. However, these aids may be rejected (not worn) because of cosmetic reasons.

5. Many clients have an unrealistic expectation of what a hearing aid can do and are often disappointed.

6. Hearing aids can make communication more difficult in noisy environments and on windy days.

7. Clients who have successfully used two hearing aids over a period of time are strong candidates for bilateral fittings.

8. All hearing aid fittings should include a 30-day free trial. In some states, it is required; in others, a trial fee may be required.

9. For new hearing aid users, the vocational justification for two hearing aids over one should be based on safety factors and/or the improvement of speech discrimination scores. New users should have (as is recommended for all clients) an independent hearing aid evaluation prior to the selection of the aid.

10. Individuals with severe visual impairments, arthritis, or grasping and finger dexterity problems generally cannot easily put batteries in an in-the-ear instrument. They may also have difficulty adjusting the volume control. Due to frustration, they may not use the aid. They also are more apt to lose an in-the-ear aid. Behind-the-ear or body instruments are more suitable for these individuals.

11. Hearing aids with a "T" (telephone) switch can be beneficial when using a hearing aid compatible phone. The "T" switch is a magnetic coil which picks up magnetic sound waves. The "T" switch is also important in the use of assistive listening systems and, for this reason, is strongly recommended, especially for behind-the-ear and body hearing aids.

12. Some audiologists, as well as licensed hearing aid dealers, are licensed to dispense hearing aids. The client should be permitted to choose the vendor where the aid is purchased, taking under consideration factors such as costs, warranties, and service reputation.

13. Clients who are successful hearing aid users are often the best judge of which hearing aid is best for them. These individuals may work directly with a hearing aid dispenser trying out different aids. The final selection should be discussed with the audiologist before purchase.

14. Insurance policies that cover lost or stolen hearing aids are available from dispensers.

15. The quality of ear mold fitting plays a significant role in the successful fitting of a hearing aid.

The fitting and use of a hearing aid is a very personalized decision by a person who is hard of hearing. Only about 23 percent of persons who could benefit from amplification have hearing aids. The percentage who wear them on a regular basis is even smaller. The only person who can really judge the benefits of a hearing aid is the person who is hard of hearing. Unfortunately, many persons who are hard of hearing will choose not to use one if they can "get by" without it.

Assistive Listening Devices. Assistive listening devices also amplify sound, but the difference between this device and a hearing aid is that the assistive listening device brings the speaker's voice **directly** into the ear of the person who is hard of hearing. It is similar to having a radio with headphones. These devices are strongly recommended for meetings, conferences, classrooms, lectures. and similar group settings.

In the lecture configuration, the speaker has a clip-on microphone attached to a small (playing card size) radio transmitter. The user has a receiver/amplifier which would fit in a shirt pocket and attaches to an ear phone. In the small meeting configuration the microphone and transmitter are in a small box set in the middle of the table where the microphone picks up all speakers' voices. In both situations, the use of the Assistive Listening Device is enhanced when the user can lip read the speakers. Therefore, speakers need to be trained to look at the persons who are hard of hearing.

Speech and Language Services. A client's clarity of speech is based on the ability to hear speech. Those individuals who never had normal hearing will have speech articulation problems, especially with high frequency sounds and voiceless sounds. If your client has never had speech and language therapy, a referral should be made for a speech and language evaluation. Sometimes a speech pathologist can help a client improve on the "clarity" of speech and help develop some speaking techniques to acquire confidence. Clients will not gain normal speech, but the goal of this service is to acquire techniques that improve clarity and speaking confidence. The emphasis here is to determine if the client's speech is or can become sufficient to meet the speaking demands of his or her occupation. If the client can benefit from a hearing aid, the aid should be purchased prior to speech therapy sessions.

Speechreading (Lip Reading). This is a tool used by persons who are hard of hearing who try to understand speech by watching lip movements. Speechreaders also pay attention to facial expressions and body language. It is easier to communicate with any person when watching his/her face. All of us speechread to some extent, and those persons who are hard of

hearing depend more on facial visual cues.

Speechreading is difficult since approximately 60 percent of the English words are classified as **homophones**. These are words that sound alike and are visually similar. An example would be the words "bat" and "mat," or "sun" and "son." There is a wide range of speechreading skills among persons who are hard of hearing because there are many factors that determine how well a person can speechread. One major factor is that some people are easier to speechread than others.

Persons who are hard of hearing learn from speechreading experience. Using visual cues, along with sound discrimination cues, improves one's ability to understand speech. A client with a newly acquired hearing loss or one who has experienced a sudden drop in hearing ability, may benefit from short-term speechreading lessons.

The focus of the speechreading plan is to teach the client only the techniques of speechreading. The client then improves on this skill through daily practice.

Vocational Selection and Training

Choosing the vocational goal and any associated training is the most difficult part of the rehabilitation process and the most crucial for successful vocational adjustment. Dr. Jerome Schein (1991), in his research, found that persons with hearing impairments have jobs in every industry in the country. The following are suggestions which may assist with vocational selection for individuals who are having difficulty making a vocational choice:

1. Obtain a good vocational evaluation from a qualified vocational evaluator who understands persons who are hard of hearing.

2. If academic/vocational training is being considered, obtain academic achievement testing to assure that the client has the skills to handle that level of training.

3. Contact the State Department of Vocational and Technical Education to find out what careers are in demand in the client's geographical area.

4. Use the Dictionary of Occupational Titles (DOT) to identify those jobs which match the capabilities of the client.

Counselors may find that people who are hard of hearing and entering employment for the first time have low job expectations. Their selection of a vocational goal below their capabilities may have resulted from low self-esteem. It is the counselors' job to help these clients make the best and most challenging vocational selections possible based on their interests, skills, and abilities.

Many adults who are hard of hearing will have already obtained vocational skills or work experiences prior to seeking rehabilitation services. The counselor's role here is to encourage or provide job retention, transfer of skills to related occupation, or additional training.

For clients who are hard of hearing, there is a need to move away from stereotypes. For example, there is a misconception that persons who hard of hearing can be placed in occupations with extremely noisy environments "because the noise will not bother them." This is simply not true! In reality, a noisy environment could be more stressful for a person who is hard of hearing with a hearing aid than for a person with normal hearing. Further, it is essential to give strong consideration to preserving the clients's residual hearing by avoiding extremely noisy environments.

The recent advancement of communication technology, computers, and assistive listening devices has increased the range of vocational opportunities for persons who are hard of hearing. The focus for vocational selection should be based on aptitudes, interests, and abilities. Reasonable accommodations, teaching techniques, and devices that are available should also be considered.

When providing vocational training, it is imperative that support services are included with the training. Examples of support services are on-the-job training and classroom instructional training.

On-The-Job-Training. This consists of a visit by the counselor and the client to the job site for the purpose of enhancing communication and identification of communication barriers. At this time,

- Job trainers should be given techniques on how to communicate with a client who is hard of hearing.
- Job trainers should "demonstrate and show," rather than "explain and tell," when working with persons who are hard of hearing.
- Benefits of an assistive listening device should be explored and tried.
- Pen and paper should be kept handy for difficult words.

Classroom Instruction Training. This consists of training the persons who is hard of hearing in a classroom setting. At this time,

- The client may benefit from preferential seating.
- Instructors should be given communication tips and things to avoid, such as turning their back to the class or walking in back of the class.
- Note taking services should always be arranged even though sign language interpreters or an assistive listening device is available.
- If a client can benefit, an assistive listening device should be provided and used.
- If a client needs an interpreter (signing or oral), it should be arranged.

- In technical courses, tutors may help clients better understand meaning, pronunciation, etc., of special vocabulary.

- If there are several instructors teaching the same course, have the client visit each instructor to determine which one he/she understands best.

Counseling and Guidance/Coping Skills

A good Individualized Written Rehabilitation Program (IWRP) for persons who are hard of hearing should include providing the client with information and techniques that will help in learning to cope with the hearing loss. Resources for coping information and techniques may be available through:

1. Self Help for Hard of Hearing support groups or the SHHH National office, or speech and hearing clinics;

2. A local audiologist who may provide this service;

3. Peer counselors from a Center for Independent Living; or

4. A vocational rehabilitation agency.

Basic Coping Skills. Some basic coping skills that should be considered are:

1. **Environmental**. Persons who are hard of hearing need assertive training in creating environments that are more conducive to communication. They must learn to evaluate the communication environment and determine what is best for them in their situation. They can do this by:

   a. Arranging for or asking that meeting be in a quiet place.

   b. Arriving early enough to get an appropriate seating for group meetings and checking out the assistive listening device, if available.

   c. Using appropriate listening devices and signal systems.

   d. Removing or reducing visual distractions such as pulling blinds.

   e. Knowing the comfort listening zone for a variety of situations (distance from speaker).

2. **Self Empowerment**.

   a. Learning to let others know when you are not hearing and let them know what they can do to help you hear.

   b. Improving speechreading skills by learning to anticipate what will be said;

looking for key words, facial expressions, and body language.

It is extremely important, as a part of coping skills, that the person learns and applies assertiveness skills in order to improve the understanding of communication.

Ancillary Vocational Services. A good IWRP needs to address all major identified vocationally related problems which could have a negative impact vocationally for clients who are hard of hearing.

Home Environment. There are a multitude of factors outside the work environment which have vocational implications. There are several devices used in the home which can assist persons who are hard of hearing vocationally. These include:

1. Amplified telephones so the client can call the employer.

2. A telecommunications device (TDD or TT) so the client can call a relay service.

3. A loud bell or flashing light so the client will know the phone is ringing when the employer calls.

4. A timer with a vibrator on the bed or, for those who do not need a vibrator, turning the clock radio "really loud" or having a clock with a strobe light alarm..

Placement

The Individually Written Rehabilitation Program (IWRP) should address identified services the client will need for successful job placement, including the possible need for job-seeking skills training. If the individual has never been in the labor market or has not looked for work in some time, a formal Job Seeking Skills Program should be considered.

As with all clients, as service delivery nears completion, job placement needs should be explored further. Many counselors find that writing a separate "placement plan" similar to an IWRP increases the likelihood of successful case closure. If so, it is written in cooperation with the client and spells out exactly what the counselor will do and what is expected of the client.

The job interview process is stressful for any person, but is especially stressful for persons who are hard of hearing. They do not know until the interview starts whether or not they will have problems hearing the interviewer. The best strategy for this situation is to prepare the client before the interview to meet anticipated problems and to assist the interviewer by providing communication tips. It is also a good teaching tool to set up some "mock" interviews so the rehabilitation counselor can make suggestions to the client through role-playing techniques.

A good vocational plan, for the client who is hard of hearing, should always make provisions for a job location analysis. That is, an on-site assessment should be made by the counselor and client to identify communication barriers which may be encountered on the job. There are basically four ways to address communication barriers: (a) communication awareness

training, (b) assistive devices or use of interpreters, (c) environment changes, and/or (d) job duties change.

Communication Awareness Training. A new job which requires communication with different individuals can be especially stressful for the person who is hard of hearing. If the client and the employer are agreeable, it is good to have a short sensitivity program for co-workers and supervisors so they can learn good communication techniques to use when talking with a person who is hard of hearing. It also gives the client an opportunity to share information about him/herself and any assistive devices found useful. In some cases, a job coach for the first several days may be justified.

Assistive Devices and Interpreter Services. There are numerous assistive devices, including assistive listening devices, which can be used as reasonable accommodations. These devices are designed to address job-related communication barriers and improve the performance of activities of daily living. Examples of these devices are:

- Flashing lights for phones
- Amplified phones
- Relay services (dual party relay)
- Closed captions - decoder
- Real-time captioning - using stenographers/court reporters
- Caption note taking using computer
- TDD/TT
- FM (Sound radio waves) assistive listening device
- Infrared (light waves) assistive listening device
- Audio loop (electromagnetic waves) assistive listening device
- Oral/sign language interpreters

An example of an occupation that would realize great benefit from assistive devices is the homemaker occupation. Some homemaking activities may be difficult for the person who is hard of hearing and who is needed as a homemaker. There are, however, a number of devices that may assist with homemaking activities:

- Hearing aids/assistive listening devices to assist with communication with children in the home and respond to urgent situations.
- Telephone assistive devices like loud bell, flashing light, amplified phones or a TT/TDD for making doctor appointments, etc.
- Baby cry alarms
- Door bell signals/flashing light systems
- Flashing smoke alarms
- Buzzers on timers for kitchen appliances
- Waking-up alarm systems

Environmental Changes. Sometimes simple changes in the environment are beneficial for persons who are hard of hearing. Examples of such changes may be:

- Moving work area to a more quiet environment

- Moving away from the glare of light
- Sound deadening the area by adding carpet, ceiling tile, window drapes.
- Installing assistive listening devices

Job Responsibility Change. Another reasonable accommodation approach is to identify those specific job responsibilities which are difficult for the person who is hard of hearing. Assigning these duties to another employee is a common accommodation. With this approach, the person who is hard of hearing assumes greater responsibility for those job duties he/she can complete. An example of this would be having one employee take phone orders and the person who is hard of hearing pack the orders instead of having both employees doing both jobs.

THE REHABILITATION CLOSURE

Importance of Follow-Up in Vocational Placement

Good follow-up is extremely important in the placement process for persons who are hard of hearing in order to assure that the client is (a) adjusting to the environment, (b) using good coping skills and assistive listening devices, and (c) meeting the expectations of the employer. Counselors should, when appropriate, check with both the frontline supervisor and the client to see if the communication issues have been resolved prior to closing case.

Postemployment Services. Within the first several months or first year of employment, the client and employer frequently need post-employment services to resolve newly identified communication problems. These needs often arise due to changes in the client's work environment, changes in job responsibilities, or changes in supervisory personnel. The goal is to provide the client who is hard of hearing the ability and confidence to resolve his or her own communication problems. However, there are situations where the assistance of a rehabilitation counselor, an audiologist, a rehabilitation engineer, or a sound technician may be advisable. With today's technology, there are reasonable accommodations that can resolve a large percent of the communication barriers for clients who are hard of hearing.

SUMMARY

Successful vocational rehabilitation of persons who are hard of hearing requires more than the fitting of a hearing aid. Often the individual is referred simply for the purchase of a hearing aid. However, functionally the individual has many more severe problems that will impede his/her successful rehabilitation. The astute counselor will do a thorough intake interview(s). The assessment must include all areas of communication difficulty, consideration of employment challenges, and placement obstacles.

Chapter V

HUMAN RESOURCE DEVELOPMENT, TRAINING, AND EDUCATION

The foregoing chapters have established that "Hard of Hearing" is an underserved population. The needs of people who are hard of hearing are clearly different and separate from those of people with early onset deafness. This requires a mind-set different from the more traditional thinking that services for individuals who are hard of hearing reside in the less severely disabled portion of the services continuum of hearing impairments. A separate body of knowledge is needed by rehabilitation professionals at all levels and in all related disciplines in order to appropriately serve this population. Training programs must be developed and conducted that will meet this diversity of need; broaden attitudinal horizons; and provide information on identification, assessment, and services for these currently underserved people.

As a result of existing and newly implemented legislation, consumers are becoming better educated and are demanding more involvement and choice in rehabilitation services. Clients who are hard of hearing will accordingly be expecting more expertise concerning their unique problems and rehabilitation solutions from vocational rehabilitation counselors and other associated rehabilitation professionals.

The reauthorization of the Rehabilitation Act is also expected to impact on services for this population. It stresses services to underserved populations and will place emphasis on provision of assistive technological devices, especially in employment settings and programs that assist employers in accommodating individuals with disabilities. Personnel will need to be trained specifically to provide rehabilitation technology services such as assessment of need, selection of, and training in use of technology.

Preservice and in-service programs must be blended to prepare upcoming and existing professionals to appropriately serve this complex and more aware population of persons who are hard of hearing.

PRESERVICE TRAINING

One of the unique features found in deafness rehabilitation is the existence of specialty training programs which focus particularly on preparing students to enter the field of deafness rehabilitation. Such programs began to develop in the 1970s to address a demonstrated need. At that time, existing rehabilitation and rehabilitation counseling programs prepared students to enter the profession as generalists. However, it was found that generalists were, for the most part, ill-prepared to meet the unique needs of deaf and hard-of-hearing individuals who were

seeking rehabilitation services. Counselors working with persons who were deaf needed a firm background in rehabilitation counseling. However, it was also found they needed specialized knowledge. Rehabilitation Counselors for the Deaf (RCDs) need knowledge concerning the psychosocial, educational, vocational, and independent living ramifications of hearing impairment. They also required the ability to converse freely with their clients in the client's chosen mode of communication, be it American Sign Language, Signed English, or more oral forms of communication. Thus, the deafness rehabilitation and deafness rehabilitation counseling programs were established to provide specialized course work and fieldwork experiences which would prepare students to provide quality rehabilitation and related services to persons with hearing impairments.

The specialty programs in deafness rehabilitation at the baccalaureate level and deafness rehabilitation counseling at the master's level typically have very full curriculum consisting of approximately two years of study. Usually these programs include both course work and fieldwork in the areas of deafness rehabilitation. The graduate programs include deafness rehabilitation counseling, counseling theory and techniques, and training in communication modalities. As such, it is a challenge for these programs to include additional information related to a specific subpopulation such as the needs of individuals who are hard of hearing. Yet, it is imperative that information and experiences related to such underserved populations be included at the preservice level so that emerging professionals can be better qualified to rectify the existing gaps in the service delivery system that render these populations underserved.

A specialty program that focuses on individuals who are hard of hearing, patterned after those described above for the deaf, would be the ideal. However, this may not be feasible under limited funding resources.

One alternate way in which preservice programs can address this need is by infusing information and experiences related to persons who are hard of hearing throughout the existing curricula for deafness rehabilitation. Courses such as psychosocial aspects of deafness can be amended to include the psychosocial ramifications of hearing loss ranging from profound deafness to mild hearing loss rather than concentrating solely on issues related to culturally deaf individuals. Similarly, courses which deal with such issues as assessment, vocational analysis and job placement, and the practice of vocational rehabilitation can include issues and concerns relative to persons who are hard of hearing. Medical Aspects of Disability courses can incorporate information related to the entire span of severity of hearing loss and can include topics related to amplification and aural rehabilitation. Fieldwork courses, including practica and internship, can and should provide students with experiences with persons who are hard of hearing as well as those who are deaf.

Other specialty programs might also consider offering a specialized course or seminar which focuses singularly on the needs of persons who are hard of hearing. Whether the information relative to this underserved population is included in a separate course or infused throughout the existing curriculum, students should receive a central core of information about persons who are hard of hearing and their needs. At a minimum, this information should include characteristics of the hard of hearing population and population demographics. Audiometric characteristics should be included as should information related to speech production and remediation and aural rehabilitation. Further, students should be exposed to the

unique psychosocial considerations of this disability, considerations which are often vastly different from those related to persons who are deaf. It is also imperative that students receive information on assistive listening devices and existing and emerging technology that is particularly useful to persons who are hard of hearing. Also needed are information and experiences that will inform and sensitize students to the vocational implications and the job placement needs of persons who are hard of hearing.

Specialty programs that focus on training professionals in the area of hearing impairment are uniquely suited to providing information and experiences which will better prepare emerging professionals to provide quality services to persons who are hard of hearing. General rehabilitation, rehabilitation counseling, vocational evaluation, and job placement training programs can also infuse information related to this population into their existing courses. Nearly every generalist program includes, at a minimum, a lecture on hearing loss, and such teaching should include information on the full spectrum of hearing loss. This lecture should define the major differences in needs between individuals who are deaf and those who are hard of hearing. Individuals who are themselves hard of hearing would be excellent guest lecturers and could be easily identified through local chapters of Self Help for Hard of Hearing People, Inc. Practicum and internship courses should also include, when possible, exposure to persons who are hard of hearing.

Finally, nonrehabilitation related preservice training programs can also enhance the provision of quality services to persons who are hard of hearing by including information relative to this population in their curricula. Baccalaureate-level and master's degree programs in such areas as audiology and special education are particularly well-suited to addressing this population in both course work and fieldwork.

Regardless of the approach used to incorporate knowledge regarding individuals who are hard of hearing, it is important that this information be presented as a separate body of knowledge and not be perceived simply as a less severe form of deafness.

IN-SERVICE TRAINING (STAFF DEVELOPMENT)

Need to Determine Who Should Receive the Training

Since they have not traditionally been considered a specialty population, clients who are hard of hearing are probably currently being served by a random combination of generalist and deaf specialist counselors. It will therefore be necessary for an agency's administration to decide whom they want to serve clients whom are hard of hearing and thus attend this training. It is important that specific staff designations are made to serve this population because this is not a "quick fix" staff development situation. It will require the agency to commit a large block of trainee time.

It makes little sense to make all counselors experts in this specialty area. However, all counselors should have a basic orientation in order to recognize a hearing deficit that is a secondary disability. Recognition is necessary as many people do not admit or perhaps recognize hearing loss as a problem. Only with an accurate and complete diagnosis can the

counselor make informed decisions concerning who should serve the client who is dually diagnosed.

Who Should Be Trained?

The counselor who is designated by the agency to take referrals of persons who are hard of hearing will need specific training. This may be a general caseload counselor or a "deaf specialist" counselor or both. These counselors should be given intensive training, modularly and over an extended period of time, on the items in the curriculum provided in Appendix E. In addition, they should be given regular training updates on technological advances, research results, and the like. It should not be assumed that the deaf specialist counselor is already knowledgeable in the service needs of clients who are hard of hearing. They more likely have a background in deafness and are not sensitized to this separate body of knowledge.

All Other Counselors

All vocational rehabilitation counselors should receive a basic orientation to the disability of hard of hearing and how it differs from deafness in terms of impact, needs, and services. The training must ensure that counselors understand that persons who are hard of hearing are not "easy cases" for vocational rehabilitation. The training will indicate that complex needs beyond the need for a hearing aid may exist that would impact on employment and warrant service intervention. The training should help the counselor recognize that often a hearing loss is a secondary disability. Further, it should develop awareness that these needs are often not understood by the client with a hearing loss.

First-Line Supervisors

Supervisors must receive an orientation to this disability and its potential impact on employability. They must understand the variety of service options that might be appropriate to this client and how an individual client who is hard of hearing fits into the picture of an Order of Selection for Services. If the supervisor does not fully comprehend the seriousness and complexity of the problems that clients who are hard of hearing present, any training given to counselors will surely be wasted when the counselor is thwarted in attempts to justify multiple services for a client who is hard of hearing under an Order of Selection for Services.

Other Administrators. Administrators should be sensitized to the needs of clients who are hard of hearing and the needed modifications in the areas of policy, practice, and training.

Vendors

Vendors are not traditionally provided disability training by state agencies. Experience has shown, however, that many vendors do not understand the unique psychosocial problems that individuals who are hard of hearing encounter. While communication enhancements can vastly improve the quality of the person's life, other problems may impede employability.

Many evaluators and vendors of communication enhancement tools and services could benefit from training. They will need basic training in uses of a full range of assistive listening

devices in employment and other settings. In addition, they need information on how their services will interface with the state agencies' services. ADA will change the availability of assistive listening devices for people in all walks of life. The persons who are hard of hearing, regardless of degree of loss, will need to have full technological access.

Others who should be considered for training are psychologists and other leaders of individual and group counseling. Currently there are few professional individual or group counseling programs that focus on assisting with stresses and coping skills for people who are hard of hearing.

Client Assistance Programs (CAP)

It is important that CAP staff be included in the basic training modules in order that they understand the needs of clients who are hard of hearing. They will need to understand and advocate for the psychosocial implications, the communication needs, and the scope of available services. They must understand the implications of an Order of Selection for Services for this disability group. In addition, they must understand the reluctance a hearing impaired person has about approaching a complaint procedure and the importance of providing adequate communication enhancements during Client/CAP contacts. CAPs should be advised to contact consumer organizations to explain their services. During those contacts, they can provide assurance that their offices and staff are accessible to persons who are hard of hearing.

Who Should Conduct the Training?

The training should be a coordinated effort among the state agency staff development coordinator, the state coordinator of services for individuals who are deaf and hard of hearing, and the Regional Rehabilitation Continuing Education Program (RRCEP). These persons cannot be expected to have the expertise to conduct the training themselves. They must develop a cadre of training experts for each of the designated topics in the curriculum.

Self Help for Hard of Hearing People, Inc., chapters should be contacted to assist with such identification of local experts in the field. In many states SHHH chapters have members who can assist with the training regarding consumer and other issues.

RRCEPs should maintain a central file of resumes of appropriate experts. State agency and RRCEP annual training plans should include targeted training in this disability area. There should be an initial intensive program followed by training updates at least annually.

What Should Be Included in the Training?

A complete outline of a suggested curriculum is provided in Appendix E. It is designed to be used modularly. The blocks should enable agencies to devote time to those subjects they consider to best fit into their operations. It also allows for varying levels of expertise among trainees. Counselors designated to serve clients who are hard of hearing, for example, would be provided with the entire training program, while other counselors would receive only the "General Information."

The curriculum presumes that the trainee already knows vocational rehabilitation; although it is developed to assist in the rehabilitation process, it does not include basic vocational rehabilitation procedures. Curriculum training modules include the following topics:

General Information: regarding individuals who are hard of hearing:

- Scope of the problem
- Basic audiological information and aural rehabilitation
- Special sub-groups
- Psychosocial effects of hearing loss on the individual, on close personal relationships, on the job
- Effects of hearing loss on communication
- Hearing aids
- Assistive listening and other technological devices
- Professionals in the hearing health field
- Consumer support groups

Specific Information: regarding rehabilitation of individuals who are hard of hearing:

- Psychological prerequisites to rehabilitation
- Principles and techniques to counseling
- Strategies for teaching employability skills
- Job site analysis and modification/accommodation
- Legal rights of employees
- Benefits
- Transitional services (school to work)
- Vocational Rehabilitation office and staff accessibility
- Service and support resources

COMMUNITY EDUCATION

Employers

The implementation of the Americans with Disabilities Act (ADA) has helped employers become aware of their obligations for accessibility. However, employers rarely know how to accomplish accessibility for hearing impaired persons. The vocational rehabilitation counselor is the ideal and logical person to assist them make reasonable accommodations. The counselors of clients who are hard of hearing must therefore be equipped to educate the employer. They need to convey information about the psychosocial and communication aspects of the impairment, provide job site assessments, and recommend job modifications and accommodations.

Consumers

Vocational rehabilitation counselors for persons who are hard of hearing should work in concert with consumer organizations for persons who are hard of hearing. Self Help for Hard

of Hearing Persons, Inc. (SHHH) has chapters in most states. Many states have multiple chapters with one person acting as the statewide SHHH coordinator. Joint training efforts can benefit both the rehabilitation professionals and the consumers. SHHH members can assist Vocational rehabilitation with direct training, consumer panels, and identification of problems and resources. Vocational rehabilitation can provide workshops for SHHH on a variety of topics including, but not limited to:

- Leadership training, self advocacy, and empowerment.
- Vocational rehabilitation access, eligibility, and services.
- Client Assistance Program--What is it? How can it be accessed?
- What should you expect from a hearing health professional?
- Benefits and other available resources.

Funding Considerations

It is important to develop long-range plans for comprehensive training activities. A staff person (most logically the coordinator of services for programs for deaf and hard of hearing clients or the human resources development coordinator, or both) should be designated to develop an operational plan with training objectives, targeted participants, responsible persons, time frames, and deadlines. The plan should have an accompanying budget and be included in the on-going Vocational Rehabilitation State agency In-Service Training Grant. It should also be included in the Annual RRCEP Training Plan and Budget.

Information regarding the vocational rehabilitation of persons who are hard of hearing could be presented at state, regional and national conferences and workshops. Such training could be presented at the National Rehabilitation Association, the American Deafness and Rehabilitation Association, Self Help for Hard of Hearing People, Inc., the Association for Late-Deafened Adults, and the Speech and Hearing Association.

The need for in-service training should be of concern for the federal RSA Office of Deafness and Communicative Disorders and regional office staff person who is responsible for this disability area. The Prime Study Group felt these federal staff should be included in training programs as presenters and as participants. They can help set training priorities and identify any available resources.

State agencies can coordinate with the services and offices associated with their state's Technology Assistance Grant recipient and with activities associated with the implementation of the Americans With Disabilities Act.

Chapter VI

RECOMMENDATIONS

A number of recommendations accrue from the preceding discussion of issues related to improving the quality of service delivery to persons who are hard of hearing. These recommendations are summarized and grouped by the intended audience. Recommendations were made to the service delivery system including agencies and institutions: the Rehabilitation Services Administration (RSA); National Institute on Disability and Rehabilitation Research (NIDRR); providers of long-term training, including the Regional Rehabilitation Continuing Education Programs (RRCEPs); state agency administrators; and State Coordinators of Services for the Deaf (SCDs). Recommendations are provided for each of these groups together with the issue upon which the recommendation is based and supporting discussion.

REHABILITATION SERVICES ADMINISTRATION

Issue: *Some confusion seems to exist related to the provision of vocational rehabilitation services to individuals who are hard of hearing where order of selection procedures are in effect, possibly excluding some persons from receiving needed services unjustifiably.*

Discussion: There is concern among both consumers who are disabled by hearing loss and many professionals who serve them, that people described as being hard of hearing may unfairly be denied vocational rehabilitation services in many states. Section 101 (a) (5) (A) of the Rehabilitation Act of 1973 was amended in 1992, requiring states to explain how they will provide services to all eligible persons. It is felt this requirement will result in more and more state agencies moving into an order of selection whereby they are required to serve "the most severely disabled" individuals first. This in itself is not the problem. The confusion on the part of many state agencies as to what constitutes a severe disability for individuals with hearing loss is the primary concern. The practice of using the RSA-911 coding definition for severely disabled, which is based solely on the degree of hearing loss, is not suitable. An individual's functional limitations and overall need for vocational rehabilitation assistance should be the primary focus in the determination of who will receive vocational rehabilitation services.

Recommendation: In line with the definition of "individuals with a severe disability" in the 1992 amended Act, RSA should provide guidelines to the state vocational rehabilitation agencies for establishing criteria to be used in determining how severely disabled individuals with hearing loss are for order of selection purposes.

Issue: *There are an inadequate number of interpreters available who are trained and skilled in oral interpreting to fulfill the needs of persons who are hard of hearing.*

Discussion: Persons who are hard of hearing more often benefit from oral interpreters than sign language interpreters, yet most interpreter training programs focus primarily on the development of sign language communication skills. As a result, there exists a paucity of qualified oral interpreters. Oral interpreting requires a set of knowledge and skills that differs significantly from sign language interpreting. Interpreting students also need practical hands-on experience in oral interpreting situations.

Recommendation: There is a need for RSA to include an emphasis on oral interpreting in all requests for proposals issued for Interpreter Training Programs and to monitor compliance with these specifications among programs receiving awards. RSA should also be encouraged to fund short-term training programs to increase interpreters' expertise in the area of oral interpreting. Additionally, there is a need to develop quality assurance standards for oral interpreters.

Issue: *Many Rehabilitation Counselors for the Deaf (RCDs) and general caseload-carrying rehabilitation counselors lack sufficient knowledge regarding the unique rehabilitation needs of persons who are hard of hearing.*

Discussion: A number of preservice and in-service training options currently exist to provide generalists and RCDs with continuing education on issues related to deafness. There are few programs that offer curricula that deal specifically with the needs of persons who are hard of hearing. RCDs are inadequately prepared by their preservice training to meet the needs of persons who are hard of hearing. However, currently they will encounter difficulty in locating programs through which to upgrade this knowledge. RCDs who enter their positions with a solid knowledge base related to this issue may also experience difficulty in upgrading their skills and remaining current for the same reason.

RSA recently funded a grant to provide short-term training regarding the rehabilitation of persons who are hard of hearing. RSA is commended for providing the funding for this national short-term training initiative. This program will serve as a model for broader training of a larger number of rehabilitation professionals.

Recommendation: RSA should be encouraged to issue Requests for Proposals to establish preservice and in-service training on issues related to the needs of persons who are hard of hearing. A portion of all training activities should include increasing the sensitivity of general and specialized counselors to the unique needs of persons who are hard of hearing.

NATIONAL INSTITUTE ON DISABILITY AND REHABILITATION RESEARCH (NIDRR)

Issue: *Insufficient research exists that studies the most effective techniques and strategies for providing rehabilitation services to persons who are hard of hearing.*

Discussion: Most of the projects currently funded by NIDRR focus on issues related to

persons who are deaf rather than those who are hard of hearing. The same holds true for articles published in major professional journals related to hearing impairment and rehabilitation and for professional meeting presentations. As a result, less is known about how to effectively serve this population as compared with what is known about providing quality services to persons who are deaf.

Recommendation: There is a need for NIDRR to fund research projects that will study effective methods of delivering rehabilitation services to persons who are hard of hearing. There is also a need to fund projects that compare the relative efficacy of different methods of delivering services to this population.

Issue: *Information on assistive technology that benefits persons who are hard of hearing is often difficult to locate, and consumers may have difficulty selecting appropriate devices which meet their needs most effectively.*

Discussion: Assistive listening devices and other technology that assist persons who are hard of hearing are often marketed by small individual enterprises. As a result, new devices are difficult for consumers and rehabilitation counselors to identify and locate. An improved marketing and distribution system is needed. Consumers are also in need of sites where not only communication needs can be assessed but also devices can be tried before a purchase is made.

Recommendation: There is a need for NIDRR to consider funding projects which investigate efficient marketing and distribution systems for these assistive devices. The agency might also consider funding, perhaps jointly with RSA, demonstration centers where assistive devices for persons who hard of hearing could be demonstrated and distributed.

STATE AGENCY ADMINISTRATORS

Issue: *The needs and interests of persons who are hard of hearing are inadequately represented in major groups which advise state vocational rehabilitation agency administrators.*

Discussion: Most state vocational rehabilitation agencies include individuals with hearing impairments as members of their consumer advisory committees or have separate advisory committees related to hearing impairment. Representatives to these groups, however, tend to better represent the needs who are deaf than those who are hard of hearing. As a result, the unique needs and concerns of persons who are hard of hearing are often underrepresented.

Recommendation: There is a need for state vocational rehabilitation agencies to add persons who are hard of hearing and/or representatives of organizations which focus on the needs of persons who are hard of hearing to their consumer advisory committees.

Issue: *State vocational rehabilitation offices should be fully accessible to persons who are hard of hearing.*

Discussion: While most vocational rehabilitation offices have installed telecommunication

devices for the deaf (TDDs) and have either staff members who sign and/or interpreters available, the unique needs of persons who are hard of hearing are often not addressed. Assistive listening devices including FM, infrared, and magnetic loop receivers need to be easily available to clients and staff. Amplified telephones should be available as well as TDDs. The office environment may also need modification to minimize ambient noise and distractions. Such modifications could include providing private interviewing rooms for clients who are hard of hearing, particularly when the physical design of the office includes large open spaces with partitions that do not limit sound, ringing telephones, and ambient street sounds.

Recommendation: There is a need for administrators and first-line supervisors to receive training that will assist them in becoming more sensitive to the environmental and technological needs of persons who are hard of hearing and to assess the appropriateness of the spaces occupied by the agency, making modifications as needed.

Issue: *A system of ongoing program evaluation is needed to assess the quality of vocational rehabilitation services being provided to persons who are hard of hearing in each state agency.*

Discussion: The model developed for enhancing services to underserved disability groups in this document can provide a framework for assessing the current quality of services to persons who are hard of hearing. After completing an evaluation, each state should set goals relative to needed improvements.

There is a need for an ongoing data-based system of program evaluation that would assess progress toward the stated service objectives. Such a system would include, at a minimum, periodic review of cases of clients who are hard of hearing and an analysis of state-level R-911 data (client data record form). Such information would allow state agency administrators to monitor the number of persons served and the quality of services provided. Analysis of such data will allow state administrators to make corrections and improvements as necessary.

Recommendation: State agency administrators should implement a program evaluation strategy to assess the quality of services delivered specifically to persons who are hard of hearing. If persons who are hard of hearing are underserved, then the administrators should develop goals and procedures for addressing the problem.

STATE COORDINATORS OF SERVICES FOR THE DEAF (SCDs)

Issue: *Leadership is needed to ensure that the ideas contained within this document are implemented in individual state vocational rehabilitation agencies.*

Discussion: The SCD is the designated expert on issues related to hearing loss within a state agency. This individual is in the most logical position to provide leadership to the agency related to improving the quality of services for persons who are hard of hearing. The SCD would be in a position to disseminate the model contained within this document to field counselors and district offices. The SCD would also be in a favorable position to develop

strategies and practices for enhancing service delivery that could then be incorporated into the state plan.

Recommendation: There is a need for SCDs to meet with state agency administrators to develop a plan for defining best practice and incorporating objectives for improving services to this population into the state plan.

Issue: *A catalyst is needed in each state to promote enhanced training related to the delivery of services to persons who are hard of hearing.*

Discussion: As training resources dwindle and the number of specific disability groups competing for these resources increases, it is critical to have an individual designated in each state agency who will advocate for training needs related to underserved populations. The SCD is in a logical position to fulfill this role regarding persons who are hard of hearing.

Recommendation: SCDs should spearhead efforts to have training related to persons who are hard of hearing included in the in-service training plan for the state. SCDs are also in an excellent position to conduct in-service training for counselors and other staff who provide services or interact with persons who are hard of hearing.

Issue: *Organizations that focus specifically on the needs of persons who are hard of hearing need to be tapped as resources to provide information related to this population and to advocate for needed changes within the service delivery system.*

Discussion: Several organizations exist that have knowledge and expertise related to the needs of persons who are hard of hearing and that can act as advocates to encourage the state agency to make modifications necessary to enhance the delivery of services to this population.

Recommendation: There is a need for SCDs to develop and maintain membership and relationships with organizations advocating for the rights of persons who are hard of hearing, including local chapters of Self Help for Hard of Hearing Persons, Inc. SCD's should be encouraged to take active roles in developing state and local chapters of these organizations where none exist.

LONG-TERM TRAINING PROGRAMS AND REGIONAL REHABILITATION CONTINUING EDUCATION PROGRAMS (RRCEPs)

Issue: *Inadequate training resources exist related to the needs of persons who are hard of hearing.*

Discussion: Training curricula have not been developed that specifically address the needs of persons who are hard of hearing. At the present time, there is an RRCEP (Arkansas) that has a one-year training grant. It will provide limited training in each of the federal regions. It is expected that this grant will develop specific curricula for groups of trainees including general rehabilitation counselors and RCDs. Other curriculum is needed for supervisors,

receptionists, vendors, interpreters, and human resource specialists. Training resources including audiovisual and written materials need to be developed and maintained in central repositories that can be easily accessed. There is also a need to identify trainers with expertise in this area in each region of the country.

Recommendation: The Arkansas RRCEPs grant needs to be expanded so that the training curricula developed are available for replication as needed. Training curriculum (such as suggested in the Appendix E) should be developed for periodic training. Long-term training programs should be encouraged to develop curricula and trainer resources that will be available for use on an ongoing basis.

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Serving People
With Epilepsy

Chapter VII

PEOPLE WITH EPILEPSY: AN UNDERSERVED DISABILITY GROUP

Chapter VII provides an overview of the medical and psychosocial aspects of epilepsy and a rationale for epilepsy as an underserved disability group. Multiple factors contribute to the fact that people with epilepsy are underserved including demographics, disability-related issues, psychosocial factors, and aspects of the service delivery system. Changes are needed in policies, practices, and training in order for the vocational rehabilitation service system to better meet the needs of people with epilepsy. These will be discussed in subsequent chapters.

EPILEPSY: A DEFINITION OF THE DISABILITY AND ITS IMPACT

Epilepsy is a common neurological disorder characterized by seizures that usually recur unpredictably in the absence of consistent provoking factors. Seizures are brief, temporary malfunctions of the brain's electrical system (EFA, 1989b) produced by a sudden excessive discharge of electrical energy between nerve cells. The burst in electrical energy may cause changes in consciousness, motor or sensory activity, and/or produce episodes of stereotyped, automatic behavior. Seizures have a sudden beginning and a natural ending as electrical activity peaks and returns to normal. Typically, seizures produce loss or alteration of consciousness for a minute or two, followed by a period of confusion. In some cases, duration of seizure activity is brief lasting only a few seconds, followed by a complete return to full awareness. Seizure types, once established, tend to follow a similar pattern in individuals over time (Wannamaker, Dreifuss, Booker, & Willmore, 1984).

Depending on the extent of the electrical discharge and the region of the brain where the disturbance originates, seizures may range from complete loss of consciousness and convulsions to only minor twitching movements. People may have one seizure type or a combination of seizure types. Although over 20 different types of seizures or seizure combinations exist, seizures are divided into two major categories--generalized and partial seizures.

Generalized Seizures

Generalized seizures affect the whole brain at the start of the seizure. Tonic-clonic (grand mal) seizures are the most familiar type; they are characterized by loss of consciousness, initial stiffening of the body, followed by pronounced jerking movements. There may be altered breathing, excessive salivation, and loss of bladder or bowel control (EFA, 1989b). Although they frequently involve a few minutes of fatigue and confusion, recovery times vary with the individual.

Another type of generalized seizure is the absence seizure (petit mal) that almost always begins in childhood and usually disappears or changes by adulthood. Absence seizures are characterized by momentary lapses in consciousness where repetitive eye blinking or a blank stare may be observed. They may occur hundreds of times daily but are difficult to recognize because of their very brief duration and the child's quick return to full awareness. Other forms of generalized seizures include myoclonic seizures (single massive jerks of the muscles) and atonic seizures that produce sudden falls.

Partial Seizures

Partial seizures begin in one part of the brain and are classified in two major groups--simple partial and complex partial. Some partial seizures develop into generalized tonic-clonic seizures as the disrupted electrical activity spreads throughout the brain.

Simple partial seizures are characterized by the relative localization of the abnormal discharge. Consciousness is not affected and symptoms can involve motor, sensory, and autonomic systems (Penry, 1986). For example, uncontrollable jerking may occur in one area of the body, but the individual remains aware. Sensory seizures may involve seeing or hearing things that do not exist or experiencing unexplained feelings of sadness, anger, joy, or fear.

With complex partial seizures, awareness is lost or substantially altered. Although they take many forms, complex partial seizures often start with a blank stare, followed by random activity. The individual may seem dazed, unaware of surroundings, and may mumble. Random actions may occur such as pulling at clothing, picking up objects, or walking around. Once established, seizure behavior in an individual is usually the same with each seizure (EFA, 1989b). Almost two-thirds of people with epilepsy have complex partial seizures (Gumnit, 1990) that are not only the most difficult to control but also the least understood. In rare cases, these seizures may involve humming, shouting, other verbalizations, and apparent fear. Following a complex partial seizure, the person is often confused and may have no memory of what happened during the episode.

Causes

In more than half of the cases of epilepsy, no cause can be found (EFA, 1989a). Seizures in which the cause is unknown are labeled "idiopathic seizures." The cases in which the cause is known are called "symptomatic." Symptomatic epilepsy may emerge in time as a result of head injuries, brain tumors, developmental brain defects, toxins, infections, vascular disturbances, or genetic conditions such as tuberous sclerosis (Gumnit, 1990; EFA, 1989a). Epilepsy frequently occurs in families with no history of the condition, but researchers have identified a genetic basis for some forms of the disorder.

Diagnosis

The first step in diagnosing a seizure disorder is obtaining a detailed history of precipitating events and seizure effects from the patient and a witness. The next step is a physical examination, with special attention paid to the neurological examination, that may uncover evidence of an organic disorder. The electroencephalogram (EEG) may show abnormal

electrical discharges in the brain and provide a more precise definition of the nature and location of the abnormal discharge (Penry, 1986). In some cases EEG results are negative because the abnormal electrical discharges are either (a) not occurring during the test or (b) not recorded because they occur in a part of the brain inaccessible to surface electrodes. Computerized tomography (CT) or magnetic resonance imaging (MRI) scans may be used to take pictures of the brain to determine if there are any growths, scars, or other physical conditions that may be causing the seizures (EFA, 1989a). Intensive telemetry monitoring may be required for people whose seizures are difficult to diagnose or control. Combined with other diagnostic strategies, video monitoring of the individual is another useful technique.

Treatment

Antiepileptic drug therapy is the most common method of treatment. Drugs do not cure epilepsy, but for many people the drugs will prevent or significantly control seizures as long as the drugs are taken regularly. The ultimate goal of prescribing antiepileptic medication is to suppress seizures without producing any other changes in the person (Rothner, 1988). Unfortunately, no drug meets these specifications completely. However, the goal of complete suppression of seizures with mild side effects is frequently achievable. In about 60 percent of all patients, the medications lead to complete control of seizures. In another 25 percent, seizures can be well controlled but side effects may occur.

According to an informational brochure from the Epilepsy Foundation of America (1989b), **Seizure Recognition and First Aid**, a number of medications have been approved by the U.S. Food and Drug Administration for the treatment of epilepsy. Currently, the medications most commonly used are phenobarbital, Dilantin (phenytoin), Zarontin (ethosuximide), Tegretol (carbamazepine), Depakote (divalprox sodium), Mysoline (primidone), Depakene (valproic acid), and Clonopin (clonazepam). Common side effects may include drowsiness, nausea, mental confusion, loss of coordination, blurred or double vision, rashes, and swelling of the gums.

Specific medications are prescribed to treat specific types of seizures. Finding the best medication(s) and dosage to achieve maximum control with minimum side effects may take some time. Monotherapy, the use of just one drug, is superior to polytherapy in most cases, although some people still must take more than one drug. Advantages of monotherapy include avoidance of adverse drug interactions, fewer side effects, better patient compliance, lower drug cost, and better seizure control (Porter, 1989). However, some individuals who experience seizures that are severe and difficult to control may need more than one drug. Surgery may be considered if seizures have not been controlled after repeated trials on antiepileptic medications. The prognosis for surgery is best when seizures begin in one small area of the brain that will not cause major problems if removed (Gumnit, 1990).

Underlying Neurological Deficits and Attendant Disabling Conditions

Neurological impairments, side effects of medications, and other disabilities in addition to epilepsy may influence individual functioning. Many people who have epilepsy do not experience intellectual or physical problems beyond the occurrence of seizures themselves. However, some people may have intellectual and perceptual, motor, or emotional limitations.

The cause, type, and location of injury to the brain may result in various symptoms in addition to epilepsy. Problems with memory may be caused by seizures, drug treatment, or both. Attention deficits and neuropsychological problems have been reported for some individuals.

The side effects of medications may also adversely affect quality of life. Such effects may appear gradually, such as deterioration in cognitive functioning, memory, attentiveness, problem solving, and personality (Penry, 1986). Although seen with almost all antiepileptic drugs, dose-related side effects will be reduced after the individual adjusts to an initial dosage. If not, a change in dosage may be necessary. Non dose-related side effects may also be experienced.

PERSONAL ADJUSTMENT

It is critical that persons with epilepsy understand their own individual condition such as the severity of their seizures, the presence of other neuropsychological deficits, the effects of medication, prior experiences in social settings, and personal attitudes toward the disorder and its effects. Some people readily accept the diagnosis of epilepsy, learn to live with it, and continue with their lives. Due mainly to their own misunderstanding and misperceptions of the condition, others with epilepsy may be inclined to deny the problem and resist its proper treatment. Some people may tend to isolate themselves from social activities due to fear of seizures or the feeling that they are "different."

In some cases, people with epilepsy learn to cope with their condition more rapidly when they are diagnosed at a young age. Their adjustment, however, depends a great deal on the attitudes and behavior of family, teachers, and friends. For others, growing up with epilepsy means growing up with barriers. Lack of acceptance, overconcern, and overprotection are common parental reactions. Fearing for the safety of their children, parents may prevent children from participating in typical childhood activities. Parental overprotection reinforces an image of being different that carries into adulthood and may produce social immaturity among other problems.

In other cases, parents may reject a child with epilepsy, conveying their disappointment about living with the challenges of the disorder. In extreme situations, this may manifest itself in anger or abuse toward the child.

Independence can be very difficult. Family and friends may expect less of the person in relation to home chores, vocational achievement, involvement in social and recreational activities, and so on. In many cases, a person's decision-making capabilities are preempted by others (Sands, 1982).

Since few people know what has happened to them during a seizure, they must rely on family members and friends who have witnessed their seizures for information. Hence, the way the person with epilepsy reacts to his or her own seizures may well reflect the responses of family members and friends.

The picture may differ somewhat when epilepsy occurs during late adolescence or

adulthood. Having experienced a lifestyle without seizures, these individuals feel that a loss has occurred. They may have doubts about themselves and need reassurance that they are capable and worthy. They may experience depression, feelings of hopelessness and helplessness, worry, guilt, irritability, tension and anxiety, physical symptoms, and a general dissatisfaction with life (Sands, 1982).

The person with epilepsy faces special adjustment problems. Goldin and Margolin (1975) discuss the characteristics that make adjustment difficult:

1. Epilepsy is sudden and episodic. No matter how well the person's seizures are controlled, there is always the remote possibility that a seizure will strike. Moreover, the time, place, and social circumstances in which the seizure will take place are unknown.

2. Seizures usually result in a loss of control. Not only is control lost during the seizure itself, but there is an implied lack of control over the occurrence of the seizure. Because society places a premium on predictability and regularity, loss of control over one's functioning becomes painful to tolerate, especially in a culture with a Puritan tradition that stresses self-control and individual responsibility.

3. The epileptic seizure itself often involves responses that are alien, bizarre, and frightening to the uninitiated.

Epilepsy: An Underserved Disability

Epilepsy is an exceptionally complex disability because of the wide variations in the types and severity of seizures, seizure frequency, causes, age of patient at onset, and responses to medical treatment. In addition, the diagnosis of epilepsy may be further complicated by the presence of other disabling conditions such as cerebral palsy, stroke, mental retardation, traumatic brain injury, or emotional disturbance. Antiepileptic drugs, like all drugs, produce a variety of side effects. Because of the complexity and variability of epilepsy, people with seizure disorders are among those underserved by vocational rehabilitation services.

People with seizure disorders are an underserved group even though most people claim to know about the disability. The problem is "what" they think they know about epilepsy. For example, a 1987 Gallup survey (LaMartina, 1989) revealed a high level of awareness (92%) of epilepsy among Americans. However, despite public awareness that the condition exists, almost half (49%) of those who responded positively to the initial question on awareness were unable to identify a cause of epilepsy, and only 19 percent identified epilepsy as being caused by brain disease or a brain disorder. Superstition and fear about epilepsy persist, adding social stigma to the difficulties people with epilepsy must confront. According to the survey, one out of three Americans still believe that having epilepsy makes other people think less of you. One out of six people polled believed that epilepsy is a form of mental illness. One in eight said that people with epilepsy should not have children, and one in six thought it was possible to tell if a person had epilepsy just by looking at him or her.

Societal Attitudes

For many people with epilepsy, societal attitudes are more devastating than the disorder itself. Negative public attitudes about epilepsy date back thousands of years and derive from a lack of understanding and misinformation about the disorder. Such negative attitudes are often shared by people with epilepsy, their family and friends, their (potential) employers, and even by medical personnel and rehabilitation workers. Thus, faulty information, with the resulting negative image for epilepsy, contributes both to the personal, social, familial, and vocational barriers of people with epilepsy and to their problems of being underserved by the vocational rehabilitation system.

DEMOGRAPHIC PERSPECTIVE

Two arguments are possible when documenting an unserved/underserved status. First, a group may be underrepresented in the vocational rehabilitation caseload with respect to its prevalence in the general population. Second, the group may be adequately represented in the vocational rehabilitation caseload, but it does not receive appropriate services due to a variety of factors.

The prevalence of epilepsy is estimated to be one to two percent in the general population, probably an underestimate because the frequency of seizure disorders increases with age and because many people with epilepsy are not inclined to disclose their condition. Researchers are concerned about the accuracy of the prevalence estimate for another reason (Fraser & Clemmons, 1983; Hauser & Hesdorffer, 1990). Hauser and Hesdorffer (1990) cited differences in case finding strategies as the principal cause for the variations in prevalence estimates. Case finding may be accomplished using either clinical data sources or samples from the general population. Following a review of epidemiological studies, Hauser and Hesdorffer concluded that the estimates of the number of people with epilepsy may be 7 to 23 percent lower than the actual prevalence depending on the data source used. Overall, they used the 7 percent figure to increase prevalence figures cited in their 1990 work.

Fraser (1983) cited data from population samples in which only one out of five people with seizure disorders ever went to a neurologist. He also quoted data from a Polish study documenting that one-third of the individuals with seizure disorders in one sample were never even treated. If estimates are based on people seeking treatment or, more specifically, treatment from a neurologist, then those estimates will seriously underestimate the actual number of people with epilepsy.

Data from the Rehabilitation Services Administration show that the state/federal program has consistently served what is considered to be the lower boundary of the number of individuals with epilepsy (see Table VII-1). It is also important to note that the data in Table VII-1 indicate a slight decrease in the number of individuals with epilepsy as a primary disability who were rehabilitated in recent years (Jacks & Toubbeh, 1975). The reasons for this trend are not known but should be further studied in order to determine why more people with epilepsy are not served by the state/federal program.

Table VII-1
Percentage of Successful Closures

Year	Primary Disability	%	Secondary Disability	%
1984	4,399 individuals	2.0		
1986	3,926 individuals	1.8		
1988	3,687 individuals	1.7	2,455 individuals	1.1
1989	3,426 individuals	1.6	2,664 individuals	1.2
1990*	3,125 individuals	1.5		

*Indicates preliminary data - Fiscal Year 1990 report not yet complete.

A demographic argument regarding the extent to which people with epilepsy are unserved presents only part of the picture. The hypothesis that people with epilepsy are unserved or underserved may be documented in a variety of other ways. For example, evidence from research will be presented in subsequent material to support the following assertions:

1. The psychological impact of epilepsy may produce personal misconceptions about the condition, denial of its impact, or overidentification with the disability. Fearing the stigma associated with disclosure, many people with epilepsy do not seek help.

2. A prolonged sense of helplessness may lead to clinical depression in certain individuals that negatively affects their participation in educational and vocational programs.

3. Because some rehabilitation professionals may need additional training to assess and meet the needs of people with epilepsy, they fail to deem some people eligible who would benefit from vocational rehabilitation services.

4. Existing resources and systems are insufficient for meeting the developmental needs of young people with epilepsy, thereby decreasing the probability that they will seek vocational services at a later date.

5. Because they are unable to apply for a driver's license, a significant number of people with epilepsy are unable to access rehabilitation services.

PSYCHOSOCIAL ISSUES

In spite of its significant ramifications, epilepsy is an invisible disability most of the time. It is, therefore, often easy for people who have epilepsy to deny the condition, even to themselves. However, the person continues to experience the underlying anxiety that a seizure

may occur, which interferes with the denial process.

People with epilepsy also experience difficulty developing a positive self-image because of the hidden and episodic nature of epilepsy. They live in an ambiguous status, never knowing when seizures may occur and how people will react. Attempting to act "as if" they do not have a seizure disorder, some people with epilepsy may not learn effective ways to adapt to and control their condition. As a result, significant others may not learn how to react to the disability and help the person manage his/her epilepsy. They may also have limited opportunities to provide the empathy, compassion, and understanding that the person needs to cope with the condition (Risch, 1975). Therefore, the hidden and episodic nature of epilepsy is yet another factor that causes people with epilepsy to be underserved.

Earlier discussions on the negative impact of social stigma clarify why people with epilepsy are afraid to disclose their epilepsy. This fear of disclosure affects both the accuracy of prevalence estimates and the likelihood that people with epilepsy will seek services. Many people with epilepsy do not want others to know that they have a seizure disorder. A brief review of the history of society's reactions to epilepsy explains why.

In 400 B.C. Hippocrates challenged the popular folklore that epilepsy was a visitation of the gods, that is, a "sacred disease." Although his view was not widely accepted, he wrote that epilepsy was a disorder of the brain (NIH, 1981). People of that time looked upon convulsing movements, blank staring, and seemingly aimless wanderings as being a symbol of closeness to the gods, and people with epilepsy were treated with reverence and respect. As time passed, the pendulum began swinging toward the other extreme. People began to look upon those with epilepsy with fear. Persons with epilepsy were believed to be consorting with devils and were incarcerated or executed.

According to Kaplan and Wyler (1983), no other condition, with the possible exception of leprosy, is associated with the same intense social stigma as epilepsy. Schneider (1988, p. 66) stated that, "epilepsy has negative connotations that far exceed those associated with illness in general. In the minds of many people, epilepsy is synonymous with highly undesirable attributes such as 'spirit possession, uncleanness, pollution, divine punishment, madness, uncontrolled violence, and criminal tendencies." Hershenson (1992) contended that these "dark ages" attributions about epilepsy are still with us today providing ample rationale for why people prefer not to disclose that they are coping with seizure disorders.

If such associations were not bad enough, people with epilepsy must also endure other limiting social stereotypes. For example, society may label people with epilepsy as stupid, dangerous, or crazy. Some people shy away from individuals with seizure disorders because they fear that epilepsy is contagious or fatal (Collins, 1992). They may think that it leads to mental retardation or illness. Others think that people with epilepsy have violent personalities.

A clear distinction exists between the public's hysterical reactions to a seizure and the best advice as to how to help a person who is having a seizure. The Epilepsy Foundation of America (1989b) advocates a series of simple steps to help a person with epilepsy during a convulsive seizure:

1. Protect the person from injury;

2. Do not put anything in the person's mouth;

3. Do not restrain the person, but turn the person on his/her side to prevent choking; and

4. Reassure the person as he/she returns to consciousness. If the seizure continues for more than 5 minutes, call an ambulance.

Fraser (1983) advocates that people normalize their response to the event of a seizure, both in terms of assisting the individual and reacting psychologically to the condition itself. Unfortunately, normalized reactions are the exception, which only heightens the stigma that the person with epilepsy must deal with socially and psychologically.

Although facts about seizure disorders are available and the public may intellectually understand the disorder better through education, powerful myths and fears prevail because of the hidden, episodic, and often dramatic manifestations of the condition. The complexity of epilepsy and its highly individualized nature make it very difficult for the public, including people with the disorder itself, to understand the nuances of how epilepsy does or does not affect an individual's abilities. Contributing to the problem of being unserved/underserved, non-disclosure is often preferred to the punishment of negative social reactions.

Life events are not the sole cause for significant psychological problems experienced by some people with epilepsy. Evidence indicates that many of the biochemical imbalances characteristic of severe depression are also common in epilepsy and that depression occurs in people with epilepsy more than in the general population or in individuals with other neurological disorders (Hauser & Hesdorffer, 1990). It may be that the stressors related to the stigma of epilepsy hasten the development of clinically significant depression. As Beck's (1976) research demonstrates, depressed people are less likely to seek help or to be involved in rehabilitation or training programs.

Psychopathology is, however, not a characteristic of most people with epilepsy. Hauser & Hesdorffer (1990) noted that the extent of psychopathology among people with seizure disorders is overestimated if data are from studies based on clinical samples rather than general population samples. Most people with epilepsy simply experience difficulty coping with the social stressors related to a hidden and episodic disability.

Because of the loss of control associated with seizures, people with epilepsy may develop feelings of passivity, dependency, and helplessness. In addition, the concern about an unexpected seizure and the necessity to comply with treatment demands can also lead to a diminished sense of independence and control. A function of social experiences shaped by the presence of a seizure disorder, these feelings are in no way conducive to exerting control over one's environment or to advocating for and securing needed rehabilitation services. As a result, people with epilepsy rely on others more than is necessary, exaggerate the seriousness of their own condition, develop self-limiting thoughts and beliefs, and lose any sense of personal control (Fraser, 1983; Hermann, Whitman, Wyler, Anton, & Vanderzwagg, 1990; Osokie, 1984).

To illustrate one type of self-limiting belief, Hermann et al. (1990) differentiated between the concepts of enacted stigma and felt stigma. Enacted stigma occurs, for example, when employers discriminate against people with epilepsy in the hiring process (Hauser & Hesdorffer, 1990). Unfortunately, many people with seizure disorders anticipate such treatment (felt stigma) and never apply for jobs in the first place. Thus, a self-fulfilling prophecy is created that serves to reinforce their pessimistic outlook.

The sheer frequency of stressors associated with epilepsy is also directly related to the incidence of psychopathology in many individuals who otherwise might have functioned adequately. In addition to the familiar examples of social stigma experienced by people with seizure disorders, Hermann et al. (1990, p. 98) cited other factors such as "the psychological consequences of coping with repeated episodes of loss of consciousness, often associated with embarrassment and loss of personal dignity; the uncertainty of never knowing when or where a seizure will occur; and the effects of all the above on the person's self-esteem and morale." In their research they also found that increased psychopathology was related both to the number of stressful life events and to the adequacy of the person's financial situation.

Social stressors and the person's reactions to them can produce certain long-term attitudes and behaviors that are not conducive to seeking rehabilitation services. Expecting dire consequences from their epilepsy (cognitive deterioration, loss of intellectual abilities, and unemployment), some people with epilepsy simply give up and remain at home. Other people become insecure and defensive, a problem possibly related to repeated rebuffs from potential employers and others. The resulting diminished feelings of self-esteem and self-efficacy can be more of a barrier to employment than the actual seizures.

Despite frequent and severe seizure activity, some people with epilepsy persist in not discussing the situation with employers, refuse to admit that they should not drive, or would rather be accused of abusing drugs than have an employer know that they are experiencing seizures. If individuals are accepting of their current seizure status, the person with whom they are interacting tends to be more at ease in relation to the condition. When a person can comfortably and succinctly discuss epilepsy with an employment interviewer, the interviewer becomes more assured. The person with epilepsy can modify the uncertainties and negative attitudes that are encountered (Sands, 1982). For employers who are covered by the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990, an open discussion of the condition as it relates to job performance is an advantage for identifying accommodations and enabling employment. Too frequently, however, employer attitudes create barriers to the person's ability to receive vocational rehabilitation services.

Employment Barriers

Employers express concerns about hiring people with epilepsy. These include concerns about customer/client reactions, Workers' Compensation rates, safety and liability, increased absenteeism, stress-induced seizures, medication side effects, ability to drive, and ability to produce at competitive levels (Kokaska & Maslow, 1986). Employers and co-workers suspect the competency of the individual, and some evidence indicates that the individual is more likely to be terminated following a seizure on the job (Hauser & Hesdorffer, 1990). In other cases, co-workers make the person feel as though others are spying on him or her (Schneider, 1988).

While there is information available to address these concerns (see Table VII-2), many employers are not reached with this information.

Table VII-2
Countering Employer Concerns

Customer/Client Reactions

- Employers do not understand how brief and unnoticeable most seizures are, if the employee should have a seizure at all. Convulsive seizures are much less likely to occur because of the effectiveness of antiepileptic medications.

Workers' Compensation Premium Rate

- A Department of Labor study showed that workers with epilepsy actually had slightly better safety records than others. Also, rates are not based on the medical histories of individual employees. Rates are based on the accident rates in an industrial group or on their actual accident records and the hazards in the industry. Second injury funds in several states limit employer liability for accidents which occur on the job among workers with epilepsy.

Safety and Liability

- The effects of seizures are very individualized. Some people never lose consciousness. Some have a predictable warning enabling them to retire to a safe place before the seizure begins. Others only have "nocturnal" seizures; they function well as long as they are awake. Often simple environmental adjustments in the work place can alleviate safety hazards.

Increased Absenteeism

- If the employee has seizures at all, he/she is more likely to do so outside of working hours. The few people who do have frequent seizures are usually very willing to make up for any lost time. Many seizures are brief in duration, and people can resume work quickly.

Stress-Induced Seizures

- Workers with epilepsy generally adapt to stress just as other workers do, with the same individual differences that other workers have. No two people are alike, so it is best not to assume that all seizures are induced by stress or by the same kind of stress.

Table VII-2
Countering Employer Concerns (continued)

Ability to Drive

- Every state licenses people with epilepsy to drive, though eligibility requirements vary. People who do not drive are usually successful in using public transit systems. Employers may not exclude someone who does not drive from consideration of a job unless driving is considered an essential function of the position.

Employment Potential

- The truth is most people with epilepsy will never have a seizure on the job. For those who do, seizures are likely to occur infrequently and are not likely to be convulsive. Further, once a seizure pattern has been established, it almost always remains consistent, allowing the individual and employer to know what to anticipate. Hence, most people, whether or not they are seizure free, can work in a wide range of occupations.

Service Delivery Concerns. Statistics on vocational outcomes indicate that people with epilepsy are underserved in relation to rehabilitation success (status 26 closures) in the federal/state vocational rehabilitation program as compared with specialized epilepsy rehabilitation programs. Fraser, Trego, and Blanchard (1984) compared the placement success of a specialized epilepsy clinic at the University of Washington with the average placement rate of selected vocational rehabilitation agencies from regions around the country. They noted that agency placement rates of people with epilepsy ranged from 8.9 percent to 20.7 percent. The specialized epilepsy program at the University of Washington achieved a 47.2 percent placement rate. Other specialized service programs for people with epilepsy such as the Epilepsy Foundation's Training and Placement Service (TAPS) have reported high placement success rates as well (see Table VII-3).

Barriers to Service

Barriers to serving people with epilepsy have been associated with the counselors' orientation toward the eligibility and employment potential of people with seizure disorders. Often people with epilepsy referred to vocational rehabilitation have not been considered vocationally impaired because they have achieved seizure control for an arbitrary period of time. Others have been considered too severely impaired to benefit from services because they have not achieved seizure control consistent with the same arbitrary standard. Inability to fit into narrow eligibility criteria has kept many people with epilepsy out of the vocational rehabilitation system. They are trying to access a vocational rehabilitation system premised on the needs of people with severe physical disabilities.

Table VII-3
Competitive Placements (at closure)
Training and Placement Service (TAPS)

Year	Number of Individuals Placed in Competitive Employment
1984	823
1986	809
1988	847
1989	867
1990	849

Counselors may be prejudiced about the employment potential of people with epilepsy. Tending to view all people with epilepsy the same, they may base their prognosis on associations with people in special care with the very worst epilepsy, often coupled with mental retardation. They may consider every person with epilepsy to have similar behavioral characteristics or even as having an "epileptic personality." They may consider people with epilepsy as "hard-to-place" although adequately served by the vocational rehabilitation system. These attitudes influence the decisions that counselors make about people with epilepsy.

According to Fraser (1983), one reason for the poor placement outcomes for people with epilepsy is the tendency to prematurely involve them in vocational training without a real understanding of their needs. People with epilepsy need diagnostic and medical treatment services. Counselors sometimes experience difficulty obtaining authorizations for full neurological evaluations, neuropsychological specific testing, and surgical interventions. Even if the resources are available for such services, counselors must also have the knowledge to determine which assessments are needed, who is best qualified to provide the assessments, and what combinations of medical and/or other interventions would produce the greatest improvements in the person's employability.

Of course, a number of issues must be understood in order to accurately assess aptitude and achievement capabilities of people with epilepsy. In testing, many people have difficulties responding to test items because of their lack of life exposure as compared to the groups on which the tests were standardized. Efforts to establish some standardized index of academic achievement or potential can be meaningless because so many young people with epilepsy are unfairly assigned to special education classes or miss large amounts of school time due to seizures (Sands, 1982).

The rehabilitation counselor's failure to understand epilepsy may lead to lack of service in other ways. For example, a counselor may have little knowledge of the treatment of epilepsy and, therefore, of the effects of antiepileptic medications on thinking and behavior. As a result, the counselor may determine a person unable to work when the real problem lies with the person's medication. Side effects of anti-epileptic medications include problems such as impaired motor functioning, short attention span, slurred speech, blurred vision, and drowsiness (Osokie, 1984; Ward, Fraser, & Troupin, 1981). In some cases the person may even appear intoxicated to the observer who is unaware of the effects of a high level of medication. Thus, without a sound understanding of epilepsy and its treatments, counselors may lack the knowledge to ask more in-depth questions of applicants that could result in more accurate eligibility determinations and more effective vocational services.

Counselors may also underestimate the need for vocational evaluation with people with epilepsy. The result is that the person may take a job which has inappropriate cognitive and social demands, eventually causing the person to lose the position. Clemmons and Dodrill (1983) described individuals with epilepsy who can make a good first impression but have poorly developed problem-solving and concept formation abilities consequently encounter severe problems in the work setting. They called for more emphasis on the assessment of the individual's neuropsychological status and the use of neurological data to identify people who need more intensive evaluation and placement services.

Many of those with chronic seizures require considerable counseling time and assessment to assist in clarifying vocational options and often a short-term work station or entry-level job to provide some experiential base to further vocational decision making (Fraser, 1983). In order to achieve better placement outcomes, counselors must take time to consider such options in the context of assessment and individualized program planning.

Stressing the rehabilitation potential of people with epilepsy, particularly if their seizures are under control, Ward et al. (1981) clarified the reasons why some counselors are more successful than others in serving people with epilepsy. They said:

Counselors who are successful in serving people with epilepsy

- Fully understand the individual's seizure disorder and can explain the implications of the condition to the person.
- Identify the person's adaptive skills and goals.
- Coach the individual in the development of social skills.
- Locate, if needed, a "seizure tolerant" work environment.
- Understand that epilepsy is an episodic condition and that the person with epilepsy needs on-the-job support from the vocational rehabilitation counselor immediately following a seizure at work.
- Help the person with epilepsy adjust to changes in medications or to the side

effects from medications. (p. 164)

Limited Mobility

Due to their seizure disorders, many people must observe restrictions in state laws with regard to applying for a driver's license. Osokie (1984) referred to this situation as a double disability in that the person must deal with the effects of epilepsy and the unavailability of transportation. In describing the life histories of many people with seizure disorders, Schneider (1988) showed how lack of access to transportation reinforces the person's dependency on family and friends. As a result, the person experiences feelings of guilt and inadequacy which further exacerbate 'asymmetric relationships' in the family (Schneider, 1988). Therefore, both physical barriers (no driver's license) and psychological barriers (feelings of dependency and guilt) stand in the way of the individual's accessing needed services.

CONCLUSION

The weight of the evidence in the literature supports the conclusion that many people with epilepsy are unserved or underserved. An examination of statistics from the Rehabilitation Services Administration (RSA) which describes the experiences of individuals with seizure disorders as a primary disability provide further evidence of "underservedness." Additionally, more in-depth discussion of the attitudes of people with epilepsy, the effects of social stigma, and the expectations of rehabilitation providers provide a framework for recommending changes in policy and practice to improve the success of people with epilepsy in the rehabilitation process.

Ironically, even though epilepsy is a complex neurological disorder, it is not the physiological effects of seizures that pose the greatest problems for people with epilepsy. Due to the misconceptions and myths that exist about epilepsy, the reactions of the people around them may pose far more serious barriers: (a) parents may have a tendency to overprotect children with seizure disorders, (b) employers may believe that people with epilepsy are poor employment risks, and (c) the general public may fear people with epilepsy due to erroneous beliefs about contagion or the perceived "dangers" of being around someone who has a seizure. Some vocational rehabilitation counselors may underestimate the employment potential of people with epilepsy and convey low expectations to them.

The end result of both the physiological and psychosocial factors related to epilepsy is that many people with seizure disorders are not receiving the vocational services that they need. In some cases, the problem is one of being unserved because they are not motivated to seek services from the vocational rehabilitation counselor. For other individuals, the problem is more one of being underserved because they do not receive the quality of assessment, planning, training, placement, and postemployment services that they need. In the ensuing chapters, many recommendations are made as to the changes needed in state and federal policy, service delivery, and in-service/preservice training programs. These changes will go a long way towards meeting the needs of people with epilepsy.

Chapter VIII

POLICY CONSIDERATIONS

Policy issues which impact the delivery of vocational rehabilitation services to people with epilepsy will be examined from both the federal and state-level perspective. In either realm, there is little research or literature available. This indicates that specific policies designed to address the unique challenges imposed by this condition simply do not exist on any wide scale basis. There are, however, a few examples suggestive of policy which the Prime Study Group identified. Some of these will be discussed in this chapter.

FEDERAL POLICY

Rehabilitation Services Administration (RSA) and the National Institute on Disability and Rehabilitation Research (NIDRR) have made a significant statement and have taken a significant step in identifying unserved and underserved populations as an issue for study by the Institute on Rehabilitation Issues (IRI). Further, the selection of people with epilepsy as a group of individuals to be included in this initial examination has potential for significant impact on policy development.

Research

In an early study (Jacks & Toubbeh, 1975), two RSA staff developed a six-item questionnaire regarding epilepsy which was sent to directors of fifty state vocational rehabilitation agencies. This survey generated forty-four (87%) responses. The most consistent response was that the main barriers to employment for people with epilepsy were attitudinal. Thirty-two (73%) of the directors felt that some vocational rehabilitation counselors had inappropriate, negative attitudes toward persons with epilepsy. Thirty (68%) felt that co-workers have similar attitudes.

State Vocational Rehabilitation Directors identified two significant areas of need. First there is a need for extensive didactic training. Most directors wanted training and involvement for some or all counselors within their state. The second need was for development, use, and support of local organizations. This was related to the need for additional general and specialized facilities including additional facilities for diagnosis and evaluation of persons with epilepsy.

At about the same time, the Commission for the Control of Epilepsy and Its Consequences (1977) reported to Congress that unemployment rates of people with epilepsy were more than double the national average. Underemployment was highlighted as an even greater problem. The Commission called for training of vocational rehabilitation counselors on special

needs relevant to epilepsy.

This historical perspective illustrates that concerns about epilepsy rehabilitation were identified many years ago. These concerns have resurfaced through this IRI project and remain just as pertinent today.

Most research which is related to the state-federal program is conducted by or funded by the National Institute on Disability and Rehabilitation Research (NIDRR). This agency administers and distributes funds in a variety of programs, including the following:

- Doctoral Research Training
- Model Spinal Cord Injury Systems
- Field Initiated Research
- Innovative Research
- Rehabilitation Engineering Centers
- Research and Training Centers
- Demonstration Projects

Among the disability groups that are targeted in various projects are:

- Individuals with spinal cord injury
- Individuals who are blind-visually impaired
- Individuals who are deaf-hearing impaired
- Individuals who are long-term mentally ill
- Individuals who are mentally retarded
- Individuals who are autistic
- Individuals who are learning disabled
- Individuals who have survived traumatic brain injury
- Individuals who have survived stroke (CVA)
- Children who are HIV infected
- Individuals with arthritics
- Individuals with low back pain
- Individuals with pressure sores
- Individuals with decubital ulcers
- Individuals who access physical therapy
- Individuals who access prosthetics/orthotics
- Individuals who access robotics

In 1990, NIDRR had a program budget of $54,318,000. However, not one NIDRR funded project focused on treatment or rehabilitation of individuals with epilepsy. This appears to the Prime Study Group as a gap in rehabilitation research efforts conducted at the national level. In the context of this examination of persons with epilepsy as an underserved population, such special projects are warranted for this group.

Training Issues

The Rehabilitation Services Administration (RSA) administers extensive programs and

resources for in-service and preservice training of service delivery personnel and for administrative and management personnel. Among these is the continuing education program which is implemented through the Regional Rehabilitation Continuing Education Programs (RRCEPs). RSA also administers short-term and long-term training programs that are established throughout the country and housed in many universities and private organizations. These programs and resources have tremendous capacity to provide training, information, and technical assistance to large numbers of consumers and service providers in a relatively short amount of time.

As related to people with epilepsy, the very complex and diverse medical aspects of epilepsy are usually only briefly touched upon in preservice training programs. Information on epilepsy is often included as a lecture in the medical aspects of a rehabilitation course that attempts to cover all disabilities in one semester. There is a compelling need for increased training on epilepsy rehabilitation on the part of RRCEPs and other in-service training programs in the absence of significant preservice training regarding epilepsy. There is a current need for widely disseminated training throughout the array of RSA resources.

The Rehabilitation Act Amendments of 1992 authorize projects to train personnel to provide services to individuals with specific disabilities or specific impediments. Included are groups of individuals who are unserved or underserved by state agencies, including Independent Living and supported employment recipients. They also authorize training projects to increase knowledge about job development and placement, supported employment, specialized services for persons with severe disabilities, and recreation.

Enhanced Training

The Study Group suggest that training programs and resources administered by NIDRR and RSA be put in priority order for training of disability groups or populations that are identified as unserved or underserved. These research and training priorities should be an initial step toward alleviating the condition of being unserved or underserved.

Specifically, the complex and diverse medical aspects of epilepsy need to be more comprehensively addressed in training programs. This need applies to both in-service and preservice training resources that are provided by the RRCEPs, by Research and Training Centers, and by long-term university training programs.

Collaboration between RSA and private organizations that provide advocacy and/or employment services for people with epilepsy could develop a comprehensive training curriculum at both the in-service and preservice level. At both levels there is a need for training regarding diagnosis, control, monitoring, and impact of this disorder.

Vocational and psychosocial concerns specific to persons with epilepsy need to be covered in the needed training. The unique dynamics that are associated with hidden, episodic, and stigmatizing disabilities need to be addressed as they specifically apply to the presence of epilepsy. This is particularly true for vocational rehabilitation counselors who are responsible for making eligibility determinations, authorizing and interpreting diagnostic reports, authorizing appropriate services, and implementing an Individualized Written Rehabilitation Program (IWRP)

toward the realization of an appropriate vocational goal. Particularly when a state vocational rehabilitation agency provides generalists counselors to serve people with epilepsy, there needs to be ongoing in-service training that provides the counselor with the knowledge that he or she requires in order to assure the appropriate, equitable, and effective delivery of vocational rehabilitation services to the uniquely challenged person with epilepsy.

Federal Policy and Direct Services

Currently within RSA there is no office or staff person with specific responsibility for ensuring appropriate services for individuals with epilepsy. However, there is a current and ongoing need to identify policy, research, and training that will better serve persons with epilepsy. While it may not be feasible to create a staff person or an office for every underserved population, RSA might establish a task force or advisory group to provide input and follow through on the recommendations contained in this report. A model might be the work group formed in 1986 to review the rehabilitation needs of individuals with long-term mental illness. A second method of increasing visibility and ensuring input of consumers and advocates in the policy making process would be to expand the existing cooperative agreement between the Epilepsy Foundation of America (EFA) and the Counsel of State Administrators in Vocational Rehabilitation (CSAVR).

Special Demonstrations and Discretionary Authorities

RSA currently has the authority to target funds to programs serving specific disability populations. They can also fund program areas such as supported employment demonstration projects. The 1992 amendments expanded this authority by including unserved and underserved language in the special demonstration authorization.

Over the last 10 years, supported employment has become a major service program with considerable emphasis in research, in discretionary funding, and in formula award funding. The supported employment data maintained by Virginia Commonwealth University do not collect data regarding the participation of people with epilepsy in supported employment. However, some information is collected through the "other disability" category. Search of this data indicates that approximately 1.8 percent of people in supported employment are people with epilepsy. Unfortunately, the supported employment data do not track secondary disabilities. Therefore, the number of persons with epilepsy is unknown although epilepsy is diagnosed in a significant number of persons with mental retardation. Further research may indicate that targeting persons with epilepsy in conjunction with another disability for supported employment services is a viable service option.

RSA has not specifically emphasized or prioritized services for individuals with epilepsy. The one example of direct RSA support for a program serving individuals with epilepsy is the Projects With Industry program of the University of Washington Epilepsy Centers (of 112 continuation projects and 13 new ones funded in 1990). The University of Washington Epilepsy Center also provides job development and job placement services for individuals with epilepsy referred through the Washington Division of Vocational Rehabilitation. The success that this program has achieved, over a number of years, demonstrates the advantages of partnerships among RSA, state vocational rehabilitation agencies, and specialized employment programs for

people with epilepsy.

Eligibility Determination

It was reported that some states use criteria related to seizure frequency when determining eligibility for services for persons with epilepsy. In some cases, an individual with active seizures could not be found eligible because the individual would be viewed as too severely disabled to be employed (Note: The Rehabilitation Amendments of 1992 may remove this feasibility question by presumptive feasibility). In other instances, if the individual's seizures are well controlled, the individual is not considered in need of services.

These difficulties may be compounded when an order of selection is in place, giving priority to individuals with the most severe disabilities. The term "most severe disability" is not defined in the Act and is specifically left to be defined by each state with input from consumers, advocates, and the state rehabilitation council. This change has the potential of creating an even greater inconsistency among states with significantly different standards applied to persons with epilepsy who reside in neighboring states.

Determining eligibility and establishing priorities for services are state responsibilities. RSA, however, through its responsibilities for interpreting statute and promulgating regulations has tremendous impact in shaping policy and practice. RSA can use this authority and its monitoring responsibilities to ensure that subjective standards based on frequency of seizures (or other arbitrary criteria) does not occur. RSA can also write a program assistance circular that offers guidance to the state agencies similar to the one developed with guidelines about whether a person with specific learning disabilities has a severe disability.

The Rehabilitation Act Amendments of 1992 recognized the need for more research into barriers to rehabilitation. It specifically authorized a provision which allows the Commissioner to award grants to agencies (public or nonprofit) to conduct a study to examine factors that have created barriers to successful rehabilitation outcomes for individuals with neurological or other related disorders. This study is to determine how the hidden or episodic nature of the disability affects eligibility and the provision of service.

As a specific disability population, individuals who have survived traumatic injury are receiving special attention in the literature and in discretionary programs. RSA recognized the underservice to this population and mobilized resources to improve services. It is possible that this technique would have the same effect on other underserved populations such as epilepsy.

STATE POLICY

Members of the Study Group were unable to find any literature or research that examines state vocational rehabilitation agency policy pertaining to providing services to people with epilepsy. Therefore, in April, 1992, the Study Group used the RehabNet communications system to inquiry if agencies had any special policies or procedures regarding persons with epilepsy. The request asked for information regarding medical exams or consultations, evaluation of rehabilitation potential, IWRP development and key services, eligibility

determination, or case closure.

Eleven responses were received including four from states that had no specific practices, policies, or procedures. Four states responded with very brief statements from policies and procedures manuals or similar documents. These statements gave the vocational rehabilitation counselor some information or guidance in medical aspects of epilepsy and how these aspects might impact the rehabilitation process. Two states responded with copies of cooperative agreements that had been developed at the state level with private, not-for-profit organizations that specialize in advocacy and other services for individuals with epilepsy. The final response was from a state that provided copies of detailed, specific eligibility requirements for individuals with epilepsy; also provided was relatively detailed information about the medical aspects of epilepsy contained in a document titled **Counselor Desk Reference**.

Since only eleven responses were received from the RehabNet inquiry, no conclusion can be made about the frequency of specialized practices or policies for serving individuals with epilepsy in state vocational rehabilitation agencies. However, it does suggest a lack of specific policy statements in the several states.

Special Policies

The state agency is responsible for developing its policies and procedures regarding service delivery to persons with impairments to employment. When special policies are developed, as indeed may be appropriate, it is essential that these not be restrictive or exclusionary. Each state agency must also determine if special policies related to serving people with epilepsy are appropriate. In instances where such policies are developed, special and specific effort must be made to assure that exclusionary practice does not result. The development and review of such policies are appropriate functions by people with epilepsy and by local or state advocacy groups.

The Rehabilitation Act calls for an individualized determination of eligibility that includes all considerations relevant to the applicant. As implied, the IWRP is also developed based upon the individual and unique needs of the consumer (client). Arbitrary standards, such as the length of time that a person has been seizure free, tend to undermine the central theme of providing individualized determinations and services.

State Plan Requirements

State vocational rehabilitation agencies are required to include public participation in the state plan and other policy development consultation (34 CFR 361.18). The agencies are also required to provide for continuing statewide studies of the needs of individuals with disabilities and how these needs may most effectively be met (29 USC 101(a)(15)). As a result of the changes in the reauthorization of the Rehabilitation Act, each state must also include in its statewide studies outreach procedures to identify and serve individuals with disabilities who are minorities and individuals with disabilities who have been unserved and underserved. This creates opportunities for greater input from individuals with epilepsy and advocacy groups.

Rehabilitation Advisory Council

As a result of the changes to the Rehabilitation Act, each state must establish a state rehabilitation advisory council, composed of consumers, providers, advocacy groups, and others. The councils are given a number of responsibilities including assisting the state's agency in establishing an order of selection if one is required. They also are to assess consumer satisfaction with the vocational rehabilitation system. Individuals with epilepsy, family members, and advocacy groups should be represented on the council and work with the council and the state agency.

In-Service Training

Identification of training needs and suggested training topics are the subjects of other sections of this chapter. However, it is important to note that states have in-service training budgets that could be used to provide training about epilepsy to staff. Current caseload statistics of people with epilepsy reflect the underserved nature of this population. The low number of people with epilepsy in the caseloads may result in a lower priority assignment on the in-service training calendar for subjects related to people with epilepsy. Deliberate efforts are necessary to incorporate into the state plan for human resource development appropriate in-service training focused on the needs of persons with epilepsy.

Cooperative Agreements

Cooperative agreements are a useful tool for increasing awareness about the needs of individuals with epilepsy in the state and improving cooperation between the state agency and organizations representing people with epilepsy. While a few states have established cooperative agreements with EFA affiliates, these agreements should be encouraged in every state where there is an epilepsy organization.

Development and Utilization of Appropriate Supportive Resources

In its State Plan for the Provision of Vocational Rehabilitation Services and in its State Facilities Plan, the state vocational rehabilitation agency has the appropriate vehicle for identifying the services, resources, and facilities that are needed to carry out the mission of the state-federal program. Special consideration should once again be provided with disability groups that have been identified as unserved/underserved. In regard to serving people with epilepsy, there are several specific considerations that should be made. Services that should be in place require qualified resources for diagnostic information such as neuropsychological evaluation, medical evaluation, and psychosocial evaluation. Appropriate resources for medical interventions, such as monitoring and possibly adjusting medications, are essential in an effective individualized program of service delivery and successful rehabilitation. Similar resources for the provision of information and referral services, as well as support services, are probably just as important. The state vocational rehabilitation agency should assess the availability of these services, utilize these services and, where not available, participate in the development of these services.

The Rehabilitation Act Amendments changed the definition of "facility" to community

rehabilitation program. The new definition is broader and will encompass many EFA affiliates. Although not traditionally viewed as "facilities," this is an opportunity for community programs such as EFAs Training and Placement Service and others to become part of the rehabilitation network in states. The state plan requirements concerning utilization of "facilities" and development and improvement authorities will now apply to programs like those run by EFA affiliates.

Chapter IX

BEST PRACTICES: PARTNERSHIPS WITH PERSONS WHO HAVE EPILEPSY

Rehabilitation counselors work with a wide variety of individuals with disabilities. Each person's disability profile is uniquely different. The job of providing effective, individualized, and economical rehabilitation services is complex and challenging. Counselors need as much perspective and practical guidance about specific disabilities as possible in order to have the competencies needed to work with populations of individuals with specific disability profiles.

Epilepsy has been discussed in this document as a highly individualized condition with some characteristics that present difficulties for both the persons seeking service and the counselor. Epilepsy is hidden, episodic, and at times, accompanied by other disabilities or underlying neurological deficits. Epilepsy is a highly stigmatized condition in our society. Every person with seizures presents different limitations and abilities upon entering the rehabilitation process.

This chapter presents some guidelines for best practices for epilepsy rehabilitation. The approach is not prescriptive; rather, it is advisory, based upon best practices that have been applied by epilepsy rehabilitation specialists.

IMPORTANCE OF CASE FINDING

Persons with epilepsy are underserved in the rehabilitation system in part because outreach to this group has not been a priority. There is a variety of key resources for conducting case finding efforts to stimulate referrals:

1. State and local offices of Vocational Rehabilitation should be in contact with state and local epilepsy service agencies. The Epilepsy Foundation of America (EFA) has over 80 affiliates, and while there are areas of the country where such agencies are not present, a great deal of potential is available for referral activity. In about half of the EFA affiliates, employment assistance is a targeted priority, and the connection with vocational rehabilitation services is natural and vital. In those localities where specialized epilepsy rehabilitation and employment programs are not operated by an EFA affiliate, the vocational rehabilitation system is the key resource for individuals who have seizures. Counselors should work with the epilepsy organization to identify persons who may benefit from the rehabilitation system.

2. Neurologists and epileptologists, in private practice, public clinics, and specialized

centers, are a source of referrals to Vocational Rehabilitation. Counselors should establish working relationships with these medical professionals.

3. Outreach initiatives in public places, such as libraries and Job Service offices, should be conducted. Again, where epilepsy organizations are present, these initiatives can be readily coordinated, often using materials available from the epilepsy agency.

4. Contact with school systems is very beneficial. School nurses, counselors, and special education coordinators may have knowledge of students who have epilepsy. They can advise those students of the availability of rehabilitation services as the young people engage in transition planning.

5. State/federal service providers may have information about individuals who have seizures because those individuals are receiving services from the agency. They may advise consumers of vocational rehabilitation service options. Some examples of such public agencies are Mental Health/Mental Retardation, Job Training Partnership Act programs, county public health services, Disability Determination sections of the Social Security administration, and others.

6. Private social/disability service agencies often have people with epilepsy in their programs. These organizations can help to identify individuals who may benefit from rehabilitation services. Examples include: comprehensive epilepsy centers, head injury programs, advocacy organizations, and voluntary health organizations.

Positive rehabilitation outcomes are clearly possible for people with epilepsy. Rehabilitation counselors should engage in active case finding efforts and should consider the following recommendations for best practice as they work with participants who have seizure disorders.

INTAKE INTERVIEW

Given the multiplicity of issues affecting employment of people with epilepsy, it is vital that the vocational rehabilitation counselor and the applicant with epilepsy spend adequate time to thoroughly discuss medical, psychosocial, and practical issues that affect rehabilitation potential. This is a comprehensive process which requires thorough dialogue at the intake interview.

More often than not, the individual with epilepsy is a candidate for successful rehabilitation if appropriate services and supports are provided. However, due to the lack of appropriate knowledge and understanding of this challenging disability, people with seizure disorders have often been denied entry into the rehabilitation system because of the belief that the severity of the disability will prevent securing and maintaining employment. With the 1992 amendments to the Vocational Rehabilitation Act, the issue of employment feasibility becomes moot except in a small percentage of cases. Section 123 (4)(A) states,

> It shall be presumed that an individual can benefit in terms of an employment outcome from vocational rehabilitation services under section 7(8)(A)(ii), unless the designated State unit can demonstrate by clear and convincing evidence that such individual is incapable of benefiting from vocational rehabilitation services in terms of employment outcome.

The change in eligibility determination will help to correct arbitrary judgments regarding an individual's feasibility for employment. On a practical level it still remains important to assess the individual's best avenue to success in employment. Persons more severely disabled by their epilepsy and other attendant disabilities may need supported employment interventions and supports. Others may need occupational skills training and job search training so that a more independent job search can be conducted.

All the key factors which have bearing on the person's vocational potential must be examined. Specific areas that should be covered at every intake appointment with an applicant who has epilepsy include:

1. Education status including how the person did in school, whether he/she enjoyed school, continue to enjoy learning, etc.

2. Special education and/or job training experience both in school and postschool.

3. Employment history: Many individuals with epilepsy have experienced difficulty with finding and keeping jobs. Often people who have seizure disorders do not seek rehabilitation assistance until they have a series of employment setbacks. Many times events related to their epilepsy in the work place create the difficulties with job finding and retention.

4. Seizure type(s): People who have epilepsy may have a number of different types of seizures. This is important information to gather as it relates to treatment plans, vocational goal-setting, job search activities, strategies for reasonable accommodation, and numerous other factors relevant to the development of an Individualized Written Rehabilitation Program.

5. Seizure frequency: Frequency of seizures is an important factor in the person's ability to maintain employment in many cases. An individual's functional limitations may be compounded by extensive seizure activity.

6. Characteristics of seizures: The way that seizures manifest themselves is highly individualized. Behaviors before, during, and after seizure activity must be known to the greatest extent possible. These characteristics have significant influence on vocational goals, ability to perform essential job duties with or without accommodation, and the need to educate employers and co-workers about the condition.

7. Medications: Understanding what medications the individual is taking for seizure control, including dosages, the person's compliance with the medication regimen,

and any experience of side effects that compromise functioning is critical. If problems with medications are identified, efforts in the diagnostic and treatment phases can be taken to remediate problems that affect employment.

8. Medical care: Many people with epilepsy cannot afford specialized care for their condition. Others live in areas of the country where such specialized medical services are unavailable. The rehabilitation counselor should explore the person's medical needs and the level of services provided. Recommendations and referrals for current diagnosis and treatment may be indicated if the counselor and applicant identify problems with medical care.

9. Other disabilities (if applicable): The counselor must identify if other disabilities, in addition to or in combination with the person's epilepsy, have an effect on diagnostic and treatment planning. These considerations extend to vocational goal-setting, job placement, and support services. Persons with multiple disability profiles will often require more comprehensive and multidisciplinary approaches to rehabilitation.

10. Transportation: Many people with epilepsy do not drive, and an individual's transportation resources may need to be evaluated and developed. If the individual has difficulty getting to service providers and employers, then the counselor will need to work with the individual to provide interim support for transportation services. The counselor will need to plan with the individual realistic employment goals with transportation limitations and expenses in mind.

11. Family/support systems: Families and significant others are often very important to individuals who have seizures. Overprotectiveness may be an issue for some individuals, while for others social supports are not available. These factors often have bearing on the person's motivation to pursue employment and capacity to follow through with plans.

When scheduling an appointment for an interview, the appointment letter should request that the applicant bring basic medical verification of epilepsy, including information about diagnosis, treatment, and employment considerations. The individual should be prepared to discuss prior employment experiences and to discuss how he/she feels that the seizure condition influences vocational goals.

As well as collecting basic information at the time of intake, it is also extremely important to observe the applicant's perceptions of his/her disability. In the early stage of the working relationship, counselor and client need to determine what interferes with the client's vocational adjustment. The counselor's aim is to identify the barriers that have frustrated the client's employment efforts in the past or threaten to do so in the future. The examination of all of these issues and factors requires a commitment of time and skill on the part of the counselor in asking strategic questions and observing applicant responses. Some of the key questions to explore include those in the following intake questionnaire.

INTAKE QUESTIONNAIRE

Seizure Information

1. What kind or kinds of seizures do you have?
2. How often do they occur?
3. How predictable are they?
4. What happens when you have a seizure? What do you do? What do you feel? How long does it last? (You may need to rely on what others tell you about your behavior during a seizure.)
5. Do you have a warning before a seizure? If so, how long does it last?
6. How do you feel after a seizure? How long does it take to recover after one?
7. What, if anything, is likely to bring a seizure on?
8. Have you ever had a seizure at work before? What was the result?
9. Have you ever injured yourself as a result of a seizure?
10. Are you satisfied with your seizure control?

Medication

1. How often do you take your medication and when? Do you ever forget to take it?
2. Do you have any side effects from your medication?
3. How long have you been taking your current medication?

Physician

1. How often do you see your doctor?
2. Does your doctor support your current job search?
3. Would your doctor place any restrictions on type of work you can do safely?

Physical Problems

1. Do you experience any problems with your memory?
2. Have you noticed difficulties with your balance, coordination, or alertness?
3. Do you know enough about your epilepsy to explain it briefly and clearly to someone else? Can you explain to someone what to do if you should have a seizure?
4. How comfortable are you about telling people you have epilepsy?

The counselor must explore and evaluate each of the various factors, independently and in combination, that present barriers to vocational success. The medical aspect of the condition, for example, may not be the primary presenting difficulty. Seizures may be in good control and adjustment to medications is not a problem. However, psychosocial issues, such as severely compromised social skills and self-esteem, brought about by social and internal reactions to epilepsy, may be standing in the way of the person's success. For others, remediation of

problems that cause difficulties with seizure control or medication side effects is central to the rehabilitation process. No single factor or predictable combination of factors can be used to assess every person with seizure disorders. Counselors should guard against using arbitrary standards, such as a seizure-free period, to assess a person's need for or progress with rehabilitation services.

ELIGIBILITY DETERMINATION

Following this in-depth intake interview, the counselor should gather additional background information to make a better determination of eligibility. Some information is readily available from medical and other allied health professionals, while in other cases the vocational rehabilitation counselor must request updated or new diagnostic information. Examples of diagnostic perspectives that may be beneficial include:

1. **General Medical Examination**. Many persons with epilepsy have not had physical exams due to lack of money and insurance if unemployed.

2. **Complete Neurological Evaluation**. A specialized neurologist in epilepsy (epileptologist) is preferred if available. Many applicants will be under medical care and will have current neurological information available.

   The counselor should provide the neurologist/ epileptologist a brief vocational history and possible vocational goal of the applicant where possible.

   The medical report from the neurologist/epileptologist should answer the following questions:

   - Seizure type(s)
   - Seizure frequency
   - Seizure manifestations
   - Age of onset
   - Other attendant disabilities and/or underlying neurological deficits
   - Medications and treatment plan
   - Vocational potential/limitations, including accommodation strategies in the work place

3. **Complete Neuropsychological/Psychological Evaluation**. Functional deficits that are commonly observed in individuals with epilepsy include perceptual-motor difficulties, memory deficits, attention deficits, cognitive deficits, spatial relationship problems, and personality disorders, among others. Some of these deficits may be observed at intake or later in the rehabilitation process and will indicate the need for formal neuropsychological or psychological assessment. The majority of applicants will benefit from this diagnostic service.

   Use of the Washington Psychosocial Seizure Inventory (WPSI) is recommended to assess psychosocial functioning of persons with epilepsy (Sands, 1982). Areas that

are examined include: family background, emotional adjustment, interpersonal adjustment, vocational adjustment, financial status, acceptance of seizures, medicine and medical management, and overall psychosocial functioning.

If, for example, an individual's memory function is severely impaired, he/she may not recall and apply previous job skills and knowledge, thus limiting employment in an area that might be considered most feasible based upon first impression. An individual may have developed profound suspicions about employment discrimination and social rejection. In this case, motivation to find a job and any approach toward pursuing employment will be greatly compromised.

If, in the course of intake interviewing, the applicant demonstrates difficulty with maintaining his/her attention, such as losing track of the topic being discussed or visual inattentiveness, this may indicate a need for evaluation. In-depth information regarding this problem will be provided through formal psychological evaluation.

4. **Vocational Evaluation**. When the aptitudes, job goals, and/or abilities of the individual are not clearly determined, then vocational evaluation is a very important tool. The evaluations should report on the person's abilities in a broad range of disciplines that relate to vocational functioning.

The number of individuals who have seizures and other disabilities is considerable, as discussed in earlier chapters. These individuals often receive services based upon the disability that presents the most apparent barrier to employment. If resources and attention are not devoted early in the rehabilitation process to identifying epilepsy-related difficulties, then inadequate planning and service delivery will follow. Functional and psychosocial factors that derive from the seizure disorder must be identified early so that the appropriate array of interventions and supports may be provided.

INDIVIDUALIZED WRITTEN REHABILITATION PROGRAM AND SERVICE DELIVERY CONSIDERATIONS

A thorough and individualized approach to gathering information from and about an applicant with epilepsy will lead to a sound determination of eligibility. One way to gather such information is to have the applicant to complete an intake questionnaire which often reveals strengths or deficits which may not be apparent in a verbal interview. Numerous factors will emerge which provide a more in-depth understanding of both the visible and the not-so-discernible aspects of the condition and other attendant disabilities.

Equipped with information that has been collected from the individual and from a variety of other sources, development of the Individualized Written Rehabilitation Program is possible. A variety of services may be indicated including medical assistance, psychosocial services, vocational training, work experience, and supported employment services, among others. Planning must be individualized and focused on both a sequence of service as well as services that are simultaneously delivered.

Seizure frequency is not the only variable which has influence on employment success. In fact, it is known that people who are having active seizures can be successful with their employment. However, a person with epilepsy whose seizures are not under control often has serious difficulty locating and maintaining employment. Many of the individuals that come to vocational rehabilitation programs requesting services go through public clinics or to a general practitioner for treatment of their epilepsy. This population generally receives less effective medical treatment and experiences poorer seizure control, problems with medications, or both.

Rehabilitation counselors should, as a matter of common practice, refer individuals with epilepsy to neurologists and specialized epilepsy centers if they are experiencing difficulties with seizure control or medication side effects. Information about such medical resources is available through the Epilepsy Foundation of America's Toll Free Service (1-800-EFA-1000). A database of over 2,000 neurologists is maintained at EFA, and referral options are available in nearly every area of the country. Neurological evaluation and new treatment strategies may lead to significantly better functional abilities of individuals, including fewer seizures and/or fewer side effects from anti-epileptic drugs. In some cases, surgical intervention is indicated, especially as this procedure becomes more available and becomes part of the total rehabilitation process for an individual who experiences severe impairment because of epilepsy.

In many cases, persons with epilepsy may benefit from psychological support services. Job search training and other services must include perspectives on the psychosocial aspects that affect successful employment. The individual may have never learned how to disclose his/her epilepsy in a positive way or may be concerned about encountering discriminatory attitudes and practices. There might also be other issues such as lack of employment history, parental over-protectiveness, transportation difficulties, unrealistic vocational expectations, or other matters that have to be taken into consideration. In most cases, such services are essential and are justified. Often a combination of interventions and supports is necessary when the counselor and individual engage in employment goal-setting, assess needs for accommodation, and conduct vocational exploration. The rehabilitation counselor's knowledge of the current labor market and specific careers that are in demand is essential to assist a person with targeting jobs that are desirable and available.

It is critical that an individualized assessment of the person's seizure condition is matched against the specific essential job duties that the person wishes to perform. In writing the vocational goal, the counselor and consumer must be as specific as possible in identifying particular vocational capacities, limitations, and other practical considerations as they relate to fundamental job requirements. For example, a person whose seizures are likely to be triggered by temperature extremes would need to carefully examine the practicality of working in an environment where such extremes occur. Such employment is not necessarily precluded, but strategies for reasonable accommodation need to be identified, if possible. In another example, a person with epilepsy who wishes to operate machinery may have no reason to avoid such an occupation if sufficient and predictable warnings precede the seizure activity and provide adequate time for the person to go to a safe place. Each person and each situation must be evaluated objectively on an individual basis during the vocational goal setting process.

Academic, business, occupational, or personal and social adjustment training may be needed to assist an individual with development of more marketable skills. Short-term training

and work experience have been identified as important interim steps toward employment, especially for those who lack a sound employment history.

Individuals who are more severely affected by their condition are candidates for supported employment services. Supported employment could involve traditional job coaching at the work site or involve a variety of off-site supports that assist the individual with job retention, such as periodic counseling or medical services.

The first several months after starting employment are particularly important to monitor. Better job retention outcomes are achieved if employer and co-worker education about seizure disorders, strategies for reasonable accommodation, and support counseling are available to help with adjustment/transition for some individuals during this initial phase. The rehabilitation counselor will help enhance the person's success if such services are provided, either directly by the agency or through epilepsy service programs such as the Epilepsy Foundation of America's network of programs.

The variety of needs and options for service for persons with seizure disorders is extensive. This does not mean, however, that individuals with epilepsy require all of these services. In fact, choices and combinations are most appropriate and are consistent with the fundamental principle of individualized service delivery. An understanding of these interventions and supports gives rehabilitation counselors and consumers a menu from which to select according to specific circumstances. Specific discussion of some of the services follows, particularly those that have been proven most beneficial in rehabilitation counselor practice and employment assistance programs targeted to persons with epilepsy:

- Neurological treatment - for better control of seizures, help with anti-seizure medications, or epilepsy surgery
- Vocational evaluation
- Psychiatric evaluation and treatment
- Vocational counseling and guidance
- Training (vocational or educational)
- Cognitive retraining (for individuals with memory deficits)
- Epilepsy education for both the client and employer/co-workers
- Personal and social adjustment training
- Work adjustment training
- Employment preparation training/job seeking skills training
- Job Club support group
- Transportation help - may be bus tokens, bus pass or transportation maintenance
- Community referrals such as epilepsy support groups, food stamps, emergency and temporary housing, vision and dental services, and others
- Supported employment
- Job placement assistance
- Postemployment assistance
- Employment follow-up to ensure the person's success in maintaining employment

Rehabilitation counselors will benefit from service coordination with local Training and Placement Services (TAPS) programs where they are available. The combined resources and

expertise of the public vocational rehabilitation system and local epilepsy service providers lead to a high percentage of favorable outcomes. The TAPS program serves as a model program for training and placement assistance.

Experience with the TAPS National Project has shown that several services are needed to successfully rehabilitate a person with epilepsy. This program is a combination of instructional programs, peer and counselor motivation and support experiences, referrals to other training and rehabilitation support services, and ongoing monitoring of each individual's progress toward his/her vocational goal. The TAPS program has led to employment success in over 55 percent of cases in the Training and Placement Service operated by EFA.

Components of TAPS training and support services include:

1. **Job Seeking Skills Training**. This portion of the program involves teaching participants the skills needed to conduct an effective job search. The JSST curriculum covers basic job readiness skill development with the unique emphasis on how epilepsy may be a relevant issue at various stages of the job search. Epilepsy education, epilepsy and employment issues, disclosure of disability, selection of a vocational goal, completion of application forms, finding job leads, getting interviews and preparing for them, interviewing skills, resume writing, and job keeping skills are the core topic areas of JSST.

2. **Access to Rehabilitation and Training Supports**. Individuals who need additional education or job skills training are provided with information about resources on training opportunities in their area. Information about JTPA IIA skills training programs, and other training and education services, is available at each TAPS office. Individuals who enter an occupational or technical training program, return to school, or receive training from a local JTPA service contractor can receive assistance from TAPS staff in obtaining unsubsidized employment during or after completion of their training experience.

3. **Job Club**. The Job Club concept, first introduced in the 1970s, has been adapted and successfully used by TAPS programs because of the investment it requires of all job seekers. Job Club meetings are held weekly and are facilitated by program staff. They offer participants opportunities to share their job-seeking experiences, receive feedback from their peers, learn new techniques, and identify new job leads. Most of all, they help to keep the participants motivated from week to week as they proceed through their search.

   Each Job Club meeting presents an activity or program. The program may be a visit from an employer to help participants with interviewing skills or to talk to them about the areas they find important when interviewing job applicants. It may include an exercise to improve a specific job-seeking skill or to help the participants handle personal challenges to accomplishing their goals.

4. **Individual Assistance**. Though the principles of the model are based upon activities achieved in groups, there are times when individual assistance is needed.

Such things as individual work on a resume, preparation for an upcoming interview, after-interview support, and other similar activities are common reasons for these sessions. Participants needing support for personal problems not related directly to the job search are generally referred to other agencies.

5. **Employer Networking**. TAPS staff educate employers in achieving a greater awareness and understanding of epilepsy. Strategies for reasonable accommodation may be required to achieve placement success. Information about employment laws which apply to persons with disabilities is shared.

In locations where an epilepsy service organization such as TAPS is available, cooperative arrangements with local vocational rehabilitation programs have been very successful in improving services to persons with epilepsy. In many cities, specialized vocational rehabilitation counselors work with an epilepsy caseload only (or in some instances, one or two other specialty areas). These counselors have extensive training in the medical and psychosocial aspects of epilepsy and are better prepared for the unique challenges faced by people with epilepsy. With the public and private programs working together, barriers to employment for people with epilepsy can be overcome in situations where one organization working alone might not be successful.

Any combination of services can be shared by the two programs. Mutual clients will benefit from the expertise of both organizations. The epilepsy programs commonly provide service of personal and social adjustment training, job seeking skills training, weekly job club meetings, job placement assistance, community referrals, post employment assistance services, and employment follow-up. The vocational rehabilitation counselor might provide neurological services (diagnostic and treatment), vocational testing and evaluation, work adjustment, vocational skills training, transportation assistance, and miscellaneous services such as eyeglasses or clothing for interviews. Counselors from both organizations provide ongoing vocational guidance and support and maintain communication with each other on the individuals's progress.

Chapter X

HUMAN RESOURCE DEVELOPMENT, TRAINING, AND EDUCATION

Education and human resource development are essential to improve rehabilitation services for individuals with epilepsy. Training initiatives will help to alleviate myths and misconceptions surrounding seizure disorders and their impact on employment. The vocational rehabilitation system and the epilepsy rehabilitation service system should establish strategies and techniques for cross-training and information exchange between their professional staffs.

Training recommendations include basic education and awareness programs regarding epilepsy and employment issues. Methods for service coordination and improved understanding of service delivery systems are crucial. Such training is needed equally on the in-service and preservice levels, and it should involve policy-makers, administrators, and counselors who have responsibility for vocational rehabilitation of persons with epilepsy.

In addition to training for rehabilitation staff, medical professionals, employers, and other allied professionals need basic education about epilepsy rehabilitation. A variety of areas should be covered, including, but not limited to, disability employment laws and practical ways to accommodate persons with epilepsy at the work place.

This multidimensional approach to training and human resource development will support and enhance the recommendations for policy and practice presented in other chapters. Individuals with epilepsy will have better opportunities for rehabilitation services that will result in successful employment outcomes.

Joint and cross-training programs for personnel in the vocational rehabilitation system, the Epilepsy Foundation of America, and other epilepsy advocacy groups at federal, state, and local levels are needed. Training of personnel who have come into contact with persons who have seizure disorders on basic issues and concerns will also greatly improve understanding of and communication about epilepsy and employment issues. Such training should focus on:

1. Physical, psychological, and functional effects of epilepsy on employment, with an emphasis on individualized versus categorical determinations of employability.

2. How to establish a physical or mental impairment that seriously limits one or more functional capacities in terms of employment outcomes.

3. Identification of effective service delivery options that will lead to employment

success.

4. Specialized program techniques that have demonstrated effectiveness in epilepsy rehabilitation.

5. The vocational rehabilitation process, including eligibility determination, diagnostic methods, the Individualized Written Rehabilitation Plan (IWRP), and other critical elements of service delivery.

6. Techniques for working with individuals with multiple disabilities which include epilepsy, such as mental retardation, traumatic brain injury, cerebral palsy, and mental illness, among others.

Epilepsy training and education for the rehabilitation professional should touch on a variety of important topics. A model curriculum for undergraduate and graduate programs for rehabilitation students, and for continuing education of vocational rehabilitation staff, should be developed. Recommended areas for such a model curriculum should include, but are not limited to:

1. The nature and cause of epilepsy
2. Epilepsy and its treatment
3. Epilepsy and society's reaction
4. Vocational counseling
5. Placement and postemployment services

The Nature and Cause of Epilepsy

Background. Epilepsy is defined as a significant and irregular discharge of neurons in the brain (Osokie, 1984). It is inclusive of a variety of conditions labeled as either general or partial seizures depending on the segments of the brain that are involved. An individual may have more than one type of seizure disorder. Reactions to epilepsy include a wide range of behavioral, physical, and emotional responses. The inclusiveness of the term epilepsy led Wright (1975) to prefer use of the term "epilepsies" to encompass the wide range of seizures, seizure frequencies, causes, ages at onset, and probability of control and treatment.

Although attributable to many different types of causes, epilepsy may occur in some people without any obvious explanation. In such a situation, the epilepsy is labeled "idiopathic." Research has established that the following factors may have a role in causing seizure disorders: genetic predisposition, brain damage, stroke, tumors, head trauma, lead poisoning, substance abuse, meningitis, encephalitis, severe cases of measles, and nutritional deficits during pregnancy and infancy (Hauser & Hesdorffer, 1990; Howell, 1978; Ward et al., 1981).

Training Topics. Based on the above information, the following topics should be discussed in the initial phase of an epilepsy education program:

1. Definition of epilepsy and seizure disorder
2. Types of seizures and their frequency and nature

3. Effects of seizures on the individual: physical, behavioral, and emotional
4. Causes of seizures

Epilepsy And Its Treatment

Background. Treatment of epilepsy is usually with antiseizure medications. With up-to-date care, as many as 80-85 percent of people with epilepsy can get control of seizures as long as medication is taken as prescribed (EFA, 1987). However, some individuals do not respond satisfactorily to the medication and are treated via surgical interventions. Approximately 70 percent of patients with epilepsy can be expected to enter remission, defined as five years without seizures; and once seizure-free for two to five years, 75 percent of those patients may be successfully withdrawn from medication (Hauser & Hesdorffer, 1990). Other individuals with epilepsy experience difficulty with seizure control regardless of treatment intervention.

With appropriate dosage levels, the medications should not interfere with the person's daily functioning. Of course, the individual's psychological reaction to the medication may be adverse; for example, some individuals may resent their loss of physical control and resulting dependency on these medications (Hermann et al., 1990).

Typically, rehabilitation professionals are not fully aware of the range of antiepileptic medications and of their effects on the individual. Improper dosages of such medication (toxicity) may produce a variety of observable symptoms that the counselor may misinterpret as caused by the disability, not the medication, leading to a decision that the person is too severely disabled to be vocationally feasible. Taking antiseizure medications may result in impaired motor functioning, loss of memory, short attention span, slurred speech, drowsiness, and blurred vision (Fraser, 1983; Hauser & Hesdorffer, 1990; Osokie, 1984). It is important that counselors understand that these symptoms may be a function of the medication so that they do not draw erroneous conclusions about the individual's possible vocational feasibility. It is important to know that it may be possible to achieve fewer such medication effects with better medical evaluation and treatment. Counselors can also explain to the individual the importance of sound neurological evaluation and treatment, including why the medications are important and the proper procedures of medical compliance.

Training Topics. The following training topics are important in any discussion of epilepsy and its treatment:

1. Types of antiseizure medications
2. Possible effects of antiseizure medication
3. The importance and practice of medical compliance
4. Ongoing neurological evaluation
5. The role of neurosurgery

Epilepsy and Society's Reactions

Background. As Schneider (1988) pointed out, disability is a category created by society that has grown to include a constellation of connotative and denotative meanings. Unfortunately, the connotative meaning of disability is often negative in the case of people with seizure

disorders. Counselors must have an appreciation of how society's reactions to the person with epilepsy, as well as their own attitudes toward the condition, shape the individual's self-definition and aspirations.

Quoting the results from National Commissions on Epilepsy in the United States and Britain, Hermann et al. (1990) enumerated the negative factors with which a person with epilepsy must cope: social stigma and discrimination, social exclusion, altered patterns of parental interactions, housing and transportation problems, and employment difficulties. Discrimination of people with epilepsy is a reality. For example, Hauser and Hesdorffer (1990) cited one study in which 22 percent of the sample reported that they were fired after the onset of epilepsy. The experiences of enacted stigma, that is, actual events of social discrimination, have a psychological impact leading to an accretion of "felt stigma" that has the potential to increase over time.

Counselors must help the individual overcome the psychological impact of stigma in order to establish a sense of optimism and realistic goals for the future. They must also understand that the combined force of these factors may produce psychopathology in some individuals that is exacerbated by the biochemical changes in the brain characteristic of epilepsy (Hauser & Hesdorffer, 1990; Hermann et al., 1990). Some individuals, therefore, may immediately respond well to rehabilitation counseling while others will require referral to neuropsychologists for specialized and/or extended evaluation services in order to identify the individual's vocational strengths and weaknesses. Some individuals with seizure disorders may benefit from psychological counseling support services before or during the rehabilitation process.

Whether offered by rehabilitation counselors or epilepsy rehabilitation specialists, social skills training is another important treatment technique. Typical social skills programs may focus on topics such as interpersonal communications, problem solving, decision making, conflict resolution, and assertion. People with epilepsy may benefit from participation in such programs because the newly developed skills will help them cope with negative social reactions toward the condition.

Training Topics. To serve people with epilepsy effectively and sensitively, counselors must appreciate the possible sociological and psychological aspects of seizure disorders. Important training topics in this regard include:

1. Disability as a social construct
2. Epilepsy as a stigmatizing label and its effects on the attitudes and expectations of service providers
3. Life experiences of the person with epilepsy and their relationship to self-imposed limitations, depression, and psychopathology for some individuals
4. Referral of people with epilepsy for psychological services
5. Social skills training for people with epilepsy

Vocational and Career Counseling

Background. Descriptions of the role and function of the vocational rehabilitation

counselor stress the centrality of vocational counseling that includes vocational evaluation, planning, and training services. Of course, the first step in counseling a person with epilepsy is the establishment of a helping relationship and a mutual understanding of the person's lifestyle and employment situation. The counselor must help the person understand the impact of the disability, medications, social reactions, and employment discrimination. With this basic understanding in place, it is appropriate to move into the vocational evaluation phase.

Although needing to apply general principles of sound vocational evaluation, rehabilitation counselors must be aware of the importance of neuropsychological factors in the life success of some people with epilepsy. In their research, Clemmons and Dodrill (1983) reported that people with epilepsy who were employed had higher scores on IQ, neuropsychological, and language skill tests than did people with epilepsy who were not employed. They stressed that these neuropsychological measures have greater potential for predicting employment than a physiological measure such as seizure type. Their finding is supported in other research as well (Hermann et al., 1990), although one should not conclude that the presence of seizure activity is insignificant. Hauser and Hesdorffer (1990) cited a study in which men with more than one seizure per year were 79 percent less likely to be employed than men with less than one seizure per.

Rehabilitation counselors, therefore, must understand the benefits of neuropsychological evaluation as a foundation for vocational planning with some people with epilepsy. Such a recommendation raises several problems. The first problem has to do with the unavailability in many areas, particularly rural areas, of neuropsychologists who conduct vocational assessments. The second has to do with the counselor's ability to structure a proper neuropsychological evaluation (i.e., ask meaningful referral questions) and understand how to apply the results. Some counselors have predispositions about the unemployability of people with epilepsy. These counselors may use arbitrary eligibility determination standards based on seizure type and frequency. Such biases unfortunately will stand in the way of these referrals even when services are affordable and available.

Setting the stage for a useful vocational assessment involves submitting appropriate referral questions to the neuropsychologist. The referral questions are based on what counselors need to know, why they need to know it, and how they plan to use it. Referral questions address how the individual's skill levels in the following areas would affect his or her social and vocational functioning (Clemmons & Dodrill, 1983):

1. Flexibility in problem solving and concept formation
2. Spatial abilities
3. Verbal and visual spatial memory
4. Perceptual abilities
5. Motor speed and coordination
6. Attention to task and attention span
7. Behavior under time pressure
8. Intelligence

Recommendations for vocational evaluation are not, however, limited to inclusion of more neuropsychological assessment. Vocational evaluation of some people with epilepsy should

include more situational assessment of a long-term nature (Fraser, 1983). Situational assessment enables the person with epilepsy to develop greater understanding of the relationship of his or her work skills and interests and specific work demands, thus enabling the person to clarify vocational goals and directions.

Presenting demands consistent with real work settings, situational assessment provides information that may help the counselor avoid erroneous conclusions about the person's vocational potential. For example, it allows for a more in-depth evaluation of the effects of medications on the person's behavior. The more in-depth functional information may contradict conclusions drawn superficially by the counselor. For example, Clemmons and Dodrill (1983) referred to the person who makes a good first impression in terms of language skills but who lacks spatial or other cognitive abilities (memory, problem solving) needed to be successful on the job. Finally, long-term situational evaluation is an excellent means for sampling the typical and optimal work adjustment behaviors of the individual.

The importance of vocational planning and training services to people with epilepsy is evident in the findings of two consumer surveys in which job counseling (Fraser, 1983) and the ability to get and keep a good job were top priority concerns of people with epilepsy. Job options and strategies for dealing with the anxiety and stigma associated with epilepsy are critical. Career development planning is essential to assist the individual with long-term goals for employment. Proper vocational counseling takes time; the individual may need to participate in on-the-job evaluation and training, career exploration groups, and individual career counseling. Vocational training rarely contributes to long-term employment if the prior steps have not been completed (Fraser, 1983).

Psychoeducational preparation is another important aspect of vocational counseling and training for people with seizure disorders. Pertinent to their desires to "get and keep a good job," psychoeducational instruction includes social skills and job seeking skills training. Topics for social skills instruction include relaxation techniques, decision making, problem solving, and assertion training. Job seeking skills training encompasses such familiar subjects as how to organize the job search, how to complete a job application and interview, and how to discuss one's health record and needs for reasonable accommodation with the employer (Gade & Toutges, 1983).

Training Topics. Training in vocational counseling responsibilities spans a wide variety of areas, for example:

1. Development of the helping relationship via interpersonal skills training
2. Principles of vocational evaluation in epilepsy rehabilitation
3. The importance of neuropsychological evaluation data and how to use them in case planning
4. The importance of situational assessment data and how to use them in case planning
5. Identification and clarification of vocational and career goals with the person with epilepsy
6. Social skills training strategies
7. Assessment and development of job seeking skills

opportunity to provide assistance could be limited by a relative lack of response from this population of individuals. Since people with epilepsy have been identified as an underserved group in the vocational rehabilitation system, and since this fact may derive from a historical experience of difficulty in accessing and succeeding through rehabilitation services, targeted initiatives for cross-training on special outreach to individuals with epilepsy is recommended.

The targeted outreach methods which are used to attract people with epilepsy should be shared and applied to the greatest extent possible throughout the national vocational rehabilitation system, especially in those localities where specialized epilepsy services are not available. Training on these methods is recommended.

SUMMARY

The individual with epilepsy often benefits from the coordination of services among many professionals. Comprehensive and consistent education and training on seizure disorders and employment have high value for successful rehabilitation. Without a common ground of understanding and a uniform commitment to individualized determinations about employment feasibility and service delivery leading to employment success, persons with epilepsy will remain underserved. Without targeted outreach efforts to encourage this group of individuals to seek rehabilitation services, persons with epilepsy will remain underserved. The problem of underservice is addressed through practical and focused training initiatives and a national effort to include more people with seizure disorders in the rehabilitation service system.

Chapter XI

RECOMMENDATIONS

The previous chapters discussed many important topics; for example, the case for epilepsy as an underserved disability, suggested rehabilitation strategies for serving people with epilepsy, state and national level policy needs, and topics for preservice and in-service training of rehabilitation personnel. In this chapter, a number of recommendations are made regarding the vocational rehabilitation of people with seizure disorders. Each recommendation is preceded by an issue or problem statement and a discussion of the issue.

REHABILITATION SERVICES ADMINISTRATION (RSA)

Issue: *Information is needed regarding provision of better vocational rehabilitation services for persons with epilepsy.*

Discussion: Many people with epilepsy who could benefit from services are not currently receiving vocational rehabilitation services. Others receive services but do not gain vocational independence. Priorities for research on epilepsy are needed that address the need for improved diagnostic, counseling, and placement techniques. RSA and the Epilepsy Foundation of America (EFA) should collaborate in development of a request for proposals regarding how to improve the provision of rehabilitation services to persons with epilepsy.

Recommendation: RSA should issue an RFP regarding the scientific study of epilepsy and best rehabilitation practices.

Issue: *Negative attitudes and discrimination continue to exist in regard to employment of persons with epilepsy.*

Discussion: Historically epilepsy has been a highly stigmatized disability. Persons with epilepsy have been ostracized, the butt of negative humor, discriminated against in employment, and denied services by agencies as too disabled. The condition of epilepsy is poorly understood. The public may react to epilepsy as a mental or emotional condition or lack of self-control. The cause and control of seizure activity is poorly understood by most individuals in the community.

Recommendation: RSA should, in collaboration with the business community, EFA, and other consumer groups, develop an effective multimedia campaign to effect positive change in employer attitudes.

Issue: *Eligibility criteria for persons with epilepsy are applied differently from state to state.*

Discussion: People with epilepsy are often deemed ineligible because their condition is considered too severe or not severe enough to warrant vocational services. Without careful individualized assessment, people with epilepsy often encounter a "double bind" in attempting to qualify for rehabilitation services. Although disabled as a result of epilepsy-related issues and experiences, many people with epilepsy may not qualify for services because one criterion such as seizure control is interpreted as evidence that no significant vocational barriers exist. Other individuals may not qualify because they are viewed to be too severely disabled due to frequency of seizures, even though seizure control is only one consideration pertinent to determining vocational feasibility.

Recommendation: Develop uniform national standards and practices for meeting the diagnostic, medical, psychosocial, and vocational needs of people with epilepsy. Promulgate these standards to the state vocational rehabilitation agencies.

Issue: *People with epilepsy need greater access to long-term and innovative rehabilitation services such as supported employment that will enable them to maintain and/or advance in their careers.*

Discussion: The importance of long-term support on the job for some people with epilepsy should not be overlooked. Data indicate a tendency among some employers to terminate people following a seizure. A need also exists to help the person and employer determine appropriate accommodations in anticipation of seizures on the job. At the present time there are no clear-cut guidelines as to the eligibility criteria for supported employment services for persons with epilepsy. Some persons with ongoing seizure activity in combination with other disabilities could benefit from supported employment services (for example, the development of natural supports in the work environment and ongoing community supports).

Recommendation: RSA should disseminate guidelines regarding eligibility criteria for Supported Employment that clearly include persons with epilepsy needing these services.

Issue: *There is need for collaboration and consumer input regarding policy and service delivery for persons with epilepsy.*

Discussion: There is a growing network of state affiliates of the Epilepsy Foundation of America (EFA) that have developed cooperative agreements with their state rehabilitation agency. On the national level, the Council of State Administrators in Vocational Rehabilitation (CSAVR) and EFA have developed and begun the implementation of a cooperative agreement. However, to date a cooperative agreement between RSA and EFA has not been developed.

Recommendation: There is a need at the national level for RSA and EFA to develop and implement a cooperative agreement in the interest of the rehabilitation of individuals with epilepsy.

Issue: *Knowledge gaps exist regarding the current "best practices" for meeting the rehabilitation needs of persons with epilepsy.*

Discussion: Vocational rehabilitation counselors need ongoing access to current

information on epilepsy. In-service trainings on epilepsy are needed that comprehensively discuss the causes and effects of epilepsy. The curriculum should include such topics as:

- The nature and cause of epilepsy, epilepsy and its treatment
- Psychosocial implications of epilepsy
- Epilepsy and society's reactions including those of vocational rehabilitation personnel
- Vocational counseling with people with epilepsy
- Placement and unique postemployment services for people with epilepsy

Employment protection of people with epilepsy under the Rehabilitation Act and the Americans with Disabilities Act should also be covered. The creation of educational modules addressing the above issues is an important provision of the CSAVR/EFA national agreement.

Recommendation: Create epilepsy education for both preservice and in-service education of rehabilitation professionals. It is suggested that an RRCEP with appropriate consumer input is an appropriate site for the development and delivery of the in-service training.

NATIONAL INSTITUTE ON DISABILITY AND REHABILITATION RESEARCH (NIDRR)

Issue: *Medical advances, recent social legislation, and the needs of persons with epilepsy have outstripped current knowledge in vocational rehabilitation.*

Discussion: There are several discrete areas in which new knowledge is essential to advance the rehabilitation of persons with epilepsy. Listed below are some of these areas.

1. Currently available incidence and prevalence data are incomplete or inaccurate, making it impossible to determine the extent to which people with epilepsy are underserved. For example, incidence and prevalence statistics based on medical or clinical-based studies result in underestimations as only a small percentage of people with seizure disorders visit a neurologist or specialized clinic for services (estimated at 20 percent in one study).

2. Data on epilepsy are needed to clarify the types of programs and services needed.

3. Funds and a mechanism are needed to increase the dissemination and adoption of successful rehabilitation techniques for people with epilepsy. The short-term funding for most demonstration projects does not enable service delivery systems to incorporate successful strategies into their ongoing programs.

4. There are several psychosocial issues that are faced by persons with epilepsy that need to be addressed. For example, stigma affects not only the behavior of others toward people with epilepsy but the behavior of some people with epilepsy as well.

5. Many persons with seizure disorders experience onset during their developmental years. However, epilepsy is not accorded the same level of resources and attention as other developmental disabilities such as mental retardation and learning disability. In part, this under-emphasis results from inadequate diagnostic services, the social stigma associated with disclosure of epilepsy, and parental lack of knowledge about the condition.

6. The ramifications of epilepsy as a developmental disability are not reflected adequately in educational and human services for school-age youth with epilepsy and their families. For young persons with epilepsy, the examination of policies and practices related to service provision in the public schools as they affect needed support services and special programs such as school-to-work transition programs are needed.

Recommendation: Each of the points listed above could be studied as individual topics. These and other research topics require long-term research and dissemination of findings. Clearly there is a need that warrants consideration of establishment of a Research and Training Center on Epilepsy.

STATE AGENCY ADMINISTRATORS

Issue: *Affiliations at the state level between state agencies and EFA are needed to improve rehabilitation services to people with epilepsy.*

Discussion: The growing network of state affiliates of the Epilepsy Foundation of America and the state rehabilitation agency should be linked in productive ways. One strategy for creating such linkages is through collaborative agreements similar to the national agreement created by CSAVR and EFA. Collaborative agreements have in the past been associated with increased numbers of people with certain disabilities being deemed eligible for services and placed successfully in competitive employment (Andrews et al., 1992).

Recommendation: State rehabilitation agencies and state affiliates of the Epilepsy Foundation of America are encouraged to establish collaborative agreements addressing service delivery issues.

Issue: *There is a continuing need for training counselors and other rehabilitation personnel about epilepsy.*

Discussion: Preservice training programs spend very little time providing training regarding epilepsy. Epilepsy is an extremely complex disorder medically (type and frequency of seizures), therapeutically (the possible unpredictable effects of antiseizure medications), and functionally (the impact of the seizure condition on the person's ability to meet the demands of his or her social and vocational environments). Counselors need information on eligibility determination and psychological evaluation with greater emphasis on development and use of neurological data. Failure to consider these factors in evaluating an individual's rehabilitation potential leads to a partial information base for the planning process. Consequently, the

subsequent vocational preparation plans are less likely to generate successful vocational placements. Service delivery mechanisms, such as supported employment or the facilitation of natural supports at the work place before closure to assist in maintaining a placement, need emphasis.

Recommendation: In-service training regarding working with persons with seizure disorders should receive increased emphasis on the in-service training calendar.

Issue: *Ensuring knowledgeable counselors within the state agency provides services to persons with epilepsy.*

Discussion: There is a significant body of knowledge regarding how to provide quality services to persons with epilepsy. The Epilepsy Foundation of America's TAPS centers and elsewhere have successfully placed over 50 percent of the persons with epilepsy that they serve by using specialty counselors. State agencies have designated and trained specialist counselors on single disabilities such as hearing impairment, traumatic brain injury, spinal cord injury, and mental retardation. These counselors become the area's resident expert on a disability and the person that other counselors turn to for answers to disability specific questions.

Recommendation: State agency administrators review staffing patterns to determine the most effective way of ensuring that counselors are knowledgeable about epilepsy or receive appropriate support.

Issue: *Some states use eligibility criteria that may inappropriately exclude some individuals with epilepsy from vocational rehabilitation services.*

Discussion: Some states require that individuals be seizure-free for a period of time before they are eligible for vocational rehabilitation. Other states deny services to persons who have been seizure-free for an arbitrary time period. Still other states may have other eligibility practices that need updating.

Recommendation: States should review policy, practice, and guidance memoranda to ensure that arbitrary exclusionary standards do not exist in policy or in practice.

Issue: *Some persons with epilepsy in conjunction with other disabilities are excellent supported employment candidates.*

Discussion: Some counselors believe supported employment is a service that should be applied only to persons who are mentally retarded or mentally ill. However, it is an appropriate service for some persons with seizures who do not meet the definition of mental retardation. Due to the combination of impairments these individuals need the supports provided in supported employment. Frequently, the development of natural supports in the work environment can aid the individual retain employment.

Recommendation: The appropriate administrator in a state agency should review the use of supported employment with certain individuals with epilepsy. The recommendation developed should be discussed with the vocational rehabilitation counseling staff.

Issue: *There is a need for community resources for the successful rehabilitation of persons with epilepsy.*

Discussion: When states conduct state needs assessment, attention should be given to the needs for community resources to support rehabilitation of persons with seizure disorders. Such resources as neuropsychologists, diagnosis of psychosocial needs and treatment, community support services, and transportation are among those needed for successful rehabilitation with this population.

Recommendation: States should assess the availability of community resources to ensure necessary support services are available. Where necessary, fees for service arrangements may be necessary to initiate cooperative arrangements with epilepsy service providers.

Issue: *Members of different professions are not aware of the latest developments in other fields that affect services to people with epilepsy.*

Discussion: Medical personnel, rehabilitation administrators and counselors, and EFA staff on the national and local levels can profit from joint training. This training should produce an exchange of information about the contributions that each profession makes to serving people with epilepsy.

Recommendation: Conduct joint training programs that involve multiple professions in discussing medical, psychosocial, and vocational aspects of epilepsy and its treatment.

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APPENDIX A

Glossary of Terms

GLOSSARY OF TERMS

ADA - Americans With Disabilities Act - The Americans With Disabilities Act of 1990 Public Law 101-336 prohibits discrimination on the basis of disability by private entities.

Adventitious Hearing Loss - A hearing impairment incurred by a child or adult who was born with normal hearing.

Air Conduction - The transmission of sound as acoustical energy to the middle ear where it is changed into mechanical energy. From the middle ear the sound travels to the internal ear and on to the brain.

ALD - Assistive Listening Device - Technical tool to assist hard of hearing people, with or without a hearing aid. It brings the speaker's voice directly to the ear. Helps to overcome the problems of distance and surrounding noise.

Alerting Devices - Signaling devices, both visual and tactile available for fire alarms, smoke detectors, phone rings, and alarm clock.

ALS - Assistive Listening System - A technical tool to assist a group of hard of hearing people.

Amplified Phone - Phones equipped with volume controls on the handset.

Audio Loop (Induction Loop) - An assistive listening device that uses electromagnetic waves for transmission. The sound from an amplifier is fed into a wire loop surrounding the seating area (or worn on the listener's neck) which broadcasts to a telecoil that serves as a receiver. Hearing aids without a T-Switch to activate a telecoil can use a special induction receiver to pick up the sound.

Audiogram - A graphic representation of the acuity of a person's hearing in each ear from a range of frequencies. Frequencies are represented along the horizontal axis of the audiogram and intensity along the vertical axis. The hearing level for each ear is recorded in decibels (loudness) for each frequency (pitch) test.

Audiology - Study of hearing and hearing disorders.

Audiologist - An individual whose primary interest is in the identification and measurement of hearing loss and the rehabilitation of those with hearing impairments.

Auditory Training - Teaching skills of utilizing one's residual hearing.

Auxiliary Aids and Services - The Department of Justice regulation provides a comprehensive list of auxiliary aids and services required by the ADA to help overcome communication barriers. Examples of auxiliary aids and services are assistive listening devices, interpreters, notetakers, captioning, etc.

Behind-the-Ear Hearing Aid - This instrument is placed behind the ear and a plastic tube connects the instrument to the ear mold.

Body Hearing Aid - This instrument has a cord and receiver and is generally the most powerful assistive instrument.

Bone Conduction - The transmission of sound to the internal ear by the cranial bones: sound vibration - cranial bones - internal ear - VIII nerve - brain (perception and comprehension of sound).

Bone Conduction Instruments - Transmit sound waves through the skull directly to the auditory nerve, by-passing the outer and middle structures of the ear. A transmitter is placed behind the ear, next to the temporal bone.

Captioned Notetaking - Also called computer-assisted notetaking; a process that permits any skilled typist, using any computer, to create large-print notes for an audience to read.

Captions - Text display of spoken dialogue and sounds; formerly known as subtitles.

Closed Captions - Captions visible only to those using a caption decoder or television with decoder chip.

Cochlear Implant - A sophisticated medical device that is inserted by an otologist by surgical means to provide sounds. Generally to qualify for Cochlear Implant, one must have severe to profound loss in both ears and receive little or no benefit from amplification devices.

Communication Access - Accommodations that provide an environment where persons with hearing loss can communicate.

Compatible Phone - A phone that generates an induction that can be picked up by a hearing aid telecoil.

Conductive Hearing Loss - Result of obstruction to the passage of sound from outer source to the inner ear. Such obstruction reduces the loudness of the sound that finally reaches the internal ear. Malfunction of the neural system is not involved. This type of hearing loss is primarily a medical problem, which, in the majority of cases, can be cleared by treatment or surgery.

Congenital Hearing Loss - A hearing impairment which exists at the time of birth. The term does not refer to the cause of the hearing problem, but relates only to the time of onset.

Deaf - Describes people who usually have no useful residual hearing and who generally employ sign language as their primary mode of communication. They may also use speechreading, hearing aids and other assistive technology to aid in communication. Based on the age at the time of loss of hearing, people who are deaf are categorized into two groups: congenitally deaf - those who were born deaf; and adventitiously deaf - those who were born with hearing, but whose sense of hearing became non-functional later in life through illness or accident.

Decibel (dB) - Unit used to express the intensity of a sound wave in logarithmic ratios to the base of ten. Sounds of different frequencies need to be from 0 - 20 dB in intensity to be heard by normal ears. If more than 20 dB is needed, then further hearing evaluation would be recommended.

Discrimination - (Speech) - Client's ability to understand words through his auditory senses.

Effective Communication - Term used in the ADA as a standard for access for people with hearing loss. A public accommodation must provide an auxiliary aid or service where necessary to ensure effective communication with individuals with disabilities. The Department of Justice strongly encourages staff of public accommodations to consult with the individuals before providing them with particular auxiliary aids or services.

Eye-Glass Hearing Aid - This instrument is built in the temple of the glasses, and a plastic tube connects the aid to the ear mold.

FM - A transmitter which broadcasts the signal by radio waves from the sound source to a receiver worn by the listener. Useful in large indoor or outdoor locations since it can cover several hundred feet and pass through physical obstructions.

Frequency - (Pitch) - Sound may be analyzed according to the number of vibrations per second caused by a sound-producing mass. The rate of vibration is measured in Hertz and is expressed as frequency. Frequencies commonly tested are: 250 Hz, 500 Hz, 2000 Hz, 4000 Hz, and 8000 Hz. The range of frequencies necessary for the understanding of speech is from 500 Hz through 2000.

Hard of Hearing - Describes people with any degree of hearing loss ranging from mild to profound. They can understand some speech sounds, with or without a hearing aid. Most people who are hard of hearing are oralists although a small number learn sign language. Generally, they are committed to participating in society by using their residual hearing plus hearing aids, speechreading, and assistive technology to aid communication.

Hearing Aid - An amplification device to assist persons with hearing loss. There are different kinds of aids distinguished by how they are worn. They may be in-the-ear (ITE), in-the-canal (ITC), behind-the-ear (BHE), or on the body. The technology is still imperfect and hearing aids do not correct hearing loss. The newest developments include programmable aids.

Infrared - An assistive listening system that uses invisible light waves to transmit the sound; frequently used in theaters.

In-the-Ear Hearing Ad - This is a very small, self-contained instrument that is worn directly in the ear.

Middle Ear - An air-filled cavity which is enclosed by the eardrum on one end and the oval window on the other end. Within the middle ear there are three small bones called the ossicle. The eustachian tube connects the middle ear cavity to the back of the nasal cavity.

Mixed Loss - The loss of hearing sensitivity due to both a conductive loss and a sensorineural loss. The result is a measurable loss by bone conduction caused by the sensorineural deficit, but an even greater loss is measured by air conduction created by both the conductive and sensorineural losses.

Open Captions - Captions visible to all viewers.

Oral Interpreting - An interpreting method in which the interpreter silently mouths the words of the speaker so they are visible on the lips. Used when the hearing impaired person uses speechreading to understand the conversation.

Otologist - A medical doctor who is concerned with the diagnosis and treatment of individuals who have an ear disease or disorders of the peripheral mechanism of hearing.

Pure Tone Average - The average of the hearing threshold at 500, 1000, and 2000 hertz. This score is expressed in decibels.

Pure Tone Tests - Measure how a person hears various tones or pitches. There are two ways in which pure tones are conducted to the internal ear to determine pure tone threshold.

Real-Time Captioning - A situation where specially-trained stenographers, using special computer equipment, create captions that appear a few seconds after the words are spoken.

Recorded Captions - Carefully prepared and timed captions recorded in advance for TV broadcast or videos.

Relay Service - Sometimes called dual party relay service; enables TDD/TT users to communicate with a non-TDD user by way of a relay service operator.

Script-Time Captioning - A by-product of newsroom script preparation and teleprompter text.

Sensorineural Loss - The loss of hearing sensitivity created by anomalies of the inner ear or of the auditory nerve beyond the inner ear.

Sign Language - The visible movements of hands, body, and face to replace the vocal elements of a spoken language.

Speech Range - The frequencies of sound across which most of the sounds of speech are present. The majority of speech sounds occur between 500 and 2000 hertz (Hz).

T-Switch - A setting on a hearing aid that can be used with a hearing-aid-compatible telephone, assistive listening device, and audio loop system. When the hearing aid is switched to "T", it activates the induction telecoil (the technical name for the "T" switch), causing the hearing aid to pick up the magnetic field generated by the "hearing-aid-compatible" telephone assistive device or audio loop system being used.

TDD/TT - (formerly TTY) - A telecommunications device for the deaf/speech impaired, used by those who cannot understand on the phone; a typewriter-like unit that shows the conversation on a screen so that it can be read.

Vertigo - A sensation of whirling or dizziness from overstimulation of the semicircular canal receptors.

Visual Alarm Signal - A visual signal (flashing light) giving notice that an audible event has taken place, for example, doorbell, fire alarm, ringing telephone. Some systems monitor a single event; others can monitor several events and indicate which event has occurred.

APPENDIX B

McCarthy-Alpiner Scale

RA-60 (REV 04/87) ITEM 4215

MICHIGAN DEPARTMENT OF EDUCATION
MICHIGAN REHABILITATION SERVICES

McCARTHY-ALPINER SCALE

CLIENT NAME		DISTRICT OFFICE
SOC. SEC. NO.	DATE	MRS COUNSELOR

INSTRUCTIONS

THE FOLLOWING QUESTIONNAIRE WILL BE USED TO HELP AUDIOLOGISTS UNDERSTAND WHAT IT IS LIKE TO HAVE A HEARING LOSS AND THE EFFECTS OF A HEARING LOSS ON YOUR LIFE. YOU ARE ASKED TO GIVE YOUR REACTION TO EACH OF THE STATEMENTS INCLUDED IN THE QUESTIONNAIRE.

YOU ARE ASKED TO MARK YOUR REACTION TO THE STATEMENT WITH A CHECKMARK UNDER THE APPROPRIATE RESPONSE. PLEASE GIVE ONLY ONE ANSWER TO EACH QUESTION.

IN MARKING YOUR ANSWER, PLEASE KEEP IN MIND THAT **ALWAYS** MEANS AT ALL TIMES OR ON ALL OCCASIONS. **USUALLY** REFERS TO GENERALLY COMMONLY, OR ORDINARILY. **SOMETIMES** MEANS OCCASIONALLY OR ON VARIOUS OCCASIONS. **RARELY** REFERS TO SELDOM OR INFREQUENTLY. **NEVER** MEANS NOT EVER OR AT NO TIME.

IF YOU ARE CURRENTLY WORKING, ANSWER QUESTIONS 19-27 BASED UPON YOUR MOST RECENT IF YOU HAVE NEVER WORKED, CHECK "NOT APPLICABLE."

ALL ANSWERS WILL BE KEPT STRICTLY CONFIDENTIAL AND USED ONLY TO HELP AUDIOLOGISTS TO UNDERSTAND WHAT IT IS LIKE TO HAVE A HEARING LOSS AND THE EFFECT HEARING LOSS HAS HAD ON YOUR LIFE.

	Always	Usually	Sometimes	Rarely	Never	Not applicable
1. I get annoyed when people do not speak loud enough for me to hear them.						
2. I get upset if I cannot hear or understand a conversation.						
3. I feel like I am isolated from things because of my hearing loss.						
4. I feel negative about life in general because of my hearing loss.						
5. I admit to most people that I have a hearing loss.						
6. I get upset when I feel that people are "mumbling."						
7. I feel very frustrated when I cannot understand a conversation.						
8. I feel that people in general understand what it is like to have a hearing loss.						

	Always	Usually	Sometimes	Rarely	Never	Not applicable
9. My hearing loss has affected my life in general.						
10. I am afraid that people will not like me if they find out I have a hearing loss.						
11. I tend to avoid people because of my hearing loss.						
12. People act annoyed when I cannot understand what is being said in a group conversation.						
13. Strangers react rudely when I do not understand.						
14. I ask a person to repeat if I do not hear or understand what they said.						
15. Group discussions make me nervous because of my hearing loss.						
16. People in general are tolerant of my hearing loss.						
17. I am not interested in group activities because of my hearing loss.						
18. My hearing loss has interfered with my job performance.						
19. I cannot perform my job well because of my hearing loss.						
20. My co-workers know what it is to have a hearing loss.						
21. I try to hide my hearing loss from my co-workers.						
22. I do not enjoy going to work because of my hearing loss.						
23. I am given credit for doing a good job at work even though I have a hearing loss.						
24. I feel more pressure at work because of my hearing loss.						
25. My employer understands what it is like to have a hearing loss.						
26. I try to hide my hearing loss from my employers.						
27. My co-workers speak loudly and clearly.						

(Revised and printed with the persmission of the authors)

APPENDIX C

Joint State Of Principles Of Cooperation

JOINT STATE OF PRINCIPLES OF COOPERATION

Self Help for Hard of Hearing People

and

Rehabilitation Services Administration

and

National Institute of Handicapped Research

and

Council of State Administrators of Vocational Rehabilitation

In the interest of the rehabilitation of individuals handicapped by hearing loss, Self Help for Hard of Hearing People, the Rehabilitation Services Administration, the National Institute of Handicapped Research and the Council of State Administrators of Vocational Rehabilitation have agreed upon the basic principles and policies of cooperation set forth in this statement. In order to fulfill the goal of this cooperative agreement, each agency has taken on specific responsibilities.

INTRODUCTION

The Rehabilitation Services Administration, Self Help for Hard of Hearing People, the National Institute of Handicapped Research and the Council of State Administrators of Vocational Rehabilitation agree that effective coordination of their resources will result in improved delivery of rehabilitation services to persons disabled by hearing loss.

While many advances have been made in vocational rehabilitation in the last several decades, many hearing impaired persons continue to be unserved or inadequately served. This is especially true for those who are the most severely handicapped. Programs and services for our large population of severely handicapped hearing impaired adults continue to be minimal in spite of the great need for them. Moreover, this large underserved or unserved group will become even larger in the 1980s and 1990s as noise continues to inundate our society.

Lower budgets for social services, including vocational rehabilitation will affect hearing impaired people as well as other handicapped people as resources available to them become fewer. The need of hearing impaired persons for unique and specialized services will aggravate their situation and almost certainly result in sharply declining employment opportunities and a lowering economic status for hearing impaired people.

The long history of cooperation between the National Association of the Deaf and the

Rehabilitation Services Administration which has produced important research and distinct improvements in service delivery to deaf people promises to be enhanced in this new Cooperative Agreement with Self Help for Hard of Hearing People. Inclusion of the National Institute of Handicapped Research and the Council of State Administrators of Vocational Rehabilitation as partners in the agreement strengthens it further in the commitments these two agencies have in the area of hearing loss.

AREAS OF COOPERATIVE AND GENERAL AGREEMENT PLANNING AND COOPERATIVE AGREEMENT WORK GROUP

It has been agreed by SHHH, the RSA, NIHR, and CSAVR that their efforts on behalf of hearing impaired people shall concentrate on short-term activities not exceeding one year. Such planning is to include consideration of the following: the role which rehabilitation research and demonstration can play in increasing and enhancing employment opportunities for hearing impaired individuals; the unique approaches which SHHH and its affiliates are taking to improve the image of hearing impaired consumers and, noncommittantly, their employment prospects; the degree to which employer awareness of the employment capabilities of hearing impaired people is being achieved; and the degree to which vocational rehabilitation has or has not been meeting the service and needs of hearing impaired individuals.

SHHH, RSA, NIHR, and CSAVR hereby agree to such short-term planning efforts on behalf of individuals handicapped by hearing loss. It is anticipated that representatives of each of these agencies shall meet no less than once a year to review progress being made in ongoing efforts, to consider needed changes, to formulate and propose policy recommendations, and to make plans for the year ahead. After each annual meeting, a report shall be prepared by the SHHH vocational rehabilitation committee which shall be made public and be open to comments.

Case Finding and Referral

SHHH affiliates (groups and chapters at local levels) shall gain a working knowledge of the services available through their State and local vocational rehabilitation agencies to assure that the hearing impaired citizens of their States shall have a ready source of information regarding the services available to them. It is equally important that State and local vocational rehabilitation agencies be familiar with the services rendered by SHHH and its affiliates.

Through such information interchange, the referral of hearing impaired persons to the agency which can best meet their needs may be facilitated. A continuing lack of understanding by the general public concerning the capabilities of people who are hearing impaired is reflected in attitudes detrimental to their welfare. In order to assure that the public has proper understanding of hearing loss and hearing impaired people, SHHH, RSA, NIHR, and CSAVR shall through this agreement work together to improve the public image of hearing impaired people. Public relations efforts should emphasize the normal intelligence, strength and mobility of hearing impaired people and their employment capabilities. The experience and expertise in the field of public relations possessed by SHHH are assets that the agency groups will wish to draw upon. It is expected that consumers will be active participants in public relations efforts.

So that hearing impaired people may be more adequately served, the agencies will cooperate in providing mutual training opportunities for professional and lay personnel. Such mutual training may be provided through:

- Undergraduate, graduate and non-degree programs offered by universities;
- Regional, State, and local in-service training courses;
- Training programs in rehabilitation centers serving hearing impaired people;
- Development of material on vocational rehabilitation of hearing impaired people for lay personnel and consumers;
- Conferences for other professional and lay personnel.

Utilization of Resources

Enhancing the provision of vocational rehabilitation services to hearing impaired persons shall be the basic goal of this Agreement. RSA and NIHR shall in pursuing this goal utilize resources such as long-term training of professionals as to the needs of hearing impaired persons; research and demonstration projects; special projects; research and training centers and projects with industry; evaluation; services to independent living and any other reasons which RSA, NIHR, and SHHH agree are important to the realization of the full human potential of individuals who are hearing impaired.

SHHH shall be available for consultations as to how other resources might best be utilized to enhance the quality of vocational rehabilitation services to hearing impaired people.

Regional Review

At least once a year, RSA will review the progress of the regional offices regarding the implementation of activities specifically assigned to them as part of the cooperative agreement work plan. SHHH shall keep its affiliates (groups and chapters) informed at all times of activities relating to the cooperative agreement including the outcome of the RSA regional review.

Systems Coordination

Individual disabled by hearing loss may have a need for a range of services, some of which may be provided by agencies other than RSA. The four cooperating agencies shall collaborate in the development and systematic utilization of formal and informal linkages with those individuals, organizations, and departments of Federal, State, and local governments having expertise capabilities and in program implementation and with the goals and objectives of RSA. Such linkages on the Federal level may include the Department of Housing and Urban Development, Department of Labor, Department of Health and Human Services, and agencies such as Special Education Programs, the Social Security Administration and any other agency deemed appropriate. These linkages will be expected to extend to all public and private resources and

shall be developed in terms of inter/intra agency relationships.

Multiple Disabilities

RSA, NIHR, SHHH, and CSAVR shall be cognizant of the needs of hearing impaired persons who have multiple disabilities. Persons included might be those who in addition to being hearing impaired are vision impaired or blind, have a motor disability, are afflicted with cerebral palsy or epilepsy, are emotionally disturbed or mentally retarded. Because these persons will have unique rehabilitation needs, RSA, SHHH, NIHR, and CSAVR will make efforts to identify and plan for hearing impaired persons having multiple disabilities.

State Agreements

Affiliates of SHHH along with State offices of vocational rehabilitation shall enter into agreements similar to the agreement between SHHH and RSA. These agreements shall be based on the local needs of hearing impaired individuals and shall assure to the maximum extent possible that persons who are hearing impaired are provided the opportunity to acquire skills which will lead to optimum employment and independent living.

GENERAL RESPONSIBILITIES OF THE COOPERATING AGENCIES

Rehabilitation Services Administration

Throughout the life of this Agreement, RSA will undertake to:

1. Encourage the State vocational rehabilitation agencies to increase their rehabilitation efforts on behalf of hearing impaired persons.

2. Direct regional offices to assist States in the development of interagency agreements with SHHH affiliates.

3. Provide vocational rehabilitation consultation to SHHH affiliates, States, and agencies in the provision of services to hearing impaired persons.

4. Encourage the use of discretionary grant funds for the increase in service to hearing impaired persons.

5. Encourage the inclusion of services to hearing impaired persons in annual State plans for operation. Maintenance of minimum standards to assure the availability of personnel trained to communicate in a hearing impaired person's mode of communication shall be emphasized.

6. Bring to the attention of NIHR, problems involved in the vocational rehabilitation of persons with handicaps caused by hearing loss that could be alleviated through new knowledge in research.

7. Conduct an annual review with NIHR, SHHH, and CSAVR on the progress of the principals in meeting the specific workplan activities agreed to.

8. Inform SHHH of the various programs available through RSA and State vocational rehabilitation agencies that may be utilized to increase services to hearing impaired persons, i.e., notices of Federal regulations as they are developed.

9. RSA shall assist SHHH in sponsoring meetings as needed along with NIHR and CSAVR and other Federal agencies which impact on the lives of hearing impaired persons to discuss how these Federal programs can best work together to improve services to persons disabled by hearing loss. These agencies shall include: the Department of Housing and Urban Development; the Department of Labor; the Department of Health and Human Services, and the Social Security Administration, the Department of Education and any other agencies deemed appropriate. Such meetings shall discuss the problems of service delivery to persons who are hearing impaired as well as the research needs of the population. It is envisioned that the meetings will result in practical recommendations to the cooperating agencies.

Responsibilities of Self Help for Hard of Hearing People

Throughout the life of the Agreement, Self Help for Hard of Hearing People will:

1. Urge its affiliates to establish and maintain close working relationships with State vocational rehabilitation agencies and their local offices, and to refer hearing impaired persons as may be appropriate.

2. Be prepared to receive referrals from vocational rehabilitation agencies and other agencies of hearing impaired persons who can benefit from SHHH-sponsored recreational, educational, and supportive services.

3. Cooperate with State vocational rehabilitation agencies in job development and placement efforts through the encouragement of local employers to hire hearing impaired persons.

4. Encourage affiliates to conduct public education programs emphasizing the importance of vocational rehabilitation and the employment capabilities of hearing impaired persons.

5. Participate in RSA sponsored meetings on hearing loss and encourage such participation in its affiliates.

6. Distribute appropriate RSA and State agency literature to its affiliates. Advocate for vocational rehabilitation in its publications, through regular featured news programs providing national information on vocational rehabilitation and hearing impaired persons.

7. Collect and evaluate information from its affiliates regarding the effectiveness of referral systems and local cooperative agreements with State vocational rehabilitation agencies.

8. Include invitations to State vocational rehabilitation personnel and related professionals to attend all appropriate meetings concerning hearing loss and hearing impaired people.

9. Encourage its affiliates to include the State Coordinator of VR Services to the Deaf and Hearing Impaired or an appropriate representative of the State agency on their local rehabilitation committee.

10. Sustain a Government Relations interest in the program and funding of vocational rehabilitation at the Federal level and expand the active interests of SHHH affiliates in vocational rehabilitation programs at the State level.

11. Develop and provide information for employers on the national and local levels.

12. Promote and provide training programs for unemployed hearing impaired people, particularly for those with the most severe handicaps.

13. Provide information to its affiliates regarding the civil rights of hearing impaired people in relation to employment and vocational training.

14. Promote the establishment of community communications programs where vocational rehabilitation and allied personnel may acquire communication skills they need to serve hearing impaired persons effectively.

15. In cooperation with RSA, sponsor workshops for affiliates to learn how to best use this Agreement. Consumers are to have an active role in the workshops.

16. Encourage its affiliates to provide referral services to the State vocational rehabilitation agencies regarding interpreters for hearing impaired people, sign language, and speech reading programs for hearing impaired persons capable of serving as rehabilitation aides.

Responsibilities of the National Institute of Handicapped Research

Throughout the life of the Agreement, NIHR will:

1. Include the study of hearing loss and hearing impaired people in research, demonstrations and related activities supported by NIHR.

2. Encourage research in rehabilitation engineering geared to meeting the needs of hearing impaired persons, and, promote the dissemination of research results.

3. Consider the needs of hearing impaired persons when making plans for research

on rehabilitation services to severely disabled individuals who are aged sixty and over, also consider conducting joint projects with the Administration on Aging, the National Institutes of Health, and other Federal agencies and private industry in areas of joint interest involving rehabilitation research related to the hearing impaired.

4. Consider the needs of hearing impaired children when implementing Section III(8) of P.L. 92-602 which calls for NIHR to "conduct a program of research related to the rehabilitation of handicapped children."

5. Solicit qualified hearing impaired persons to participate in their peer review process.

Responsibilities of CSAVR

Throughout the life of this agreement, CSAVR will encourage State vocational rehabilitation agencies to engage in the following activities:

1. Stimulate an increase in the number of hearing impaired persons rehabilitated each year.

2. Encourage and prepare the State agency staff to develop, organize, and expand programs of services to hearing impaired persons.

3. Develop interagency agreements with affiliates of SHHH.

4. Work with SHHH affiliates to develop close working relationships and to identify hearing impaired persons in each State who may need or can benefit from vocational rehabilitation.

5. Establish a state advisory committee on vocational rehabilitation services to hearing impaired people to include representatives of SHHH affiliates.

6. Include in the agency staffing, a State coordinator on Vocational Rehabilitation Services to the Hearing Impaired and rehabilitation counselors trained to work with hearing impaired people.

7. Participate in regional and short-term training in deafness rehabilitation, involving in such training SHHH affiliate staff and resource personnel; and assign state Agency Coordinators of Services to Deaf Clients to the task of assisting in the planning and implementing of such training.

8. The CSAVR shall continue and support its Committee on Rehabilitation of Deaf People; a SHHH officer shall serve on the committee for hearing impaired people.

9. The CSAVR through its Committee on Rehabilitation of Deaf People shall at the

request of the other cooperating agencies undertake timely studies on State vocational rehabilitation services to hearing impaired people.

10. Through its Committee on Rehabilitation of Deaf People, CSAVR shall maintain close working relationships with the Registry of Interpreters for the Deaf, the American Deafness and Rehabilitation Association and other agencies involved with the vocation rehabilitation of hearing impaired persons.

REVIEW OF AGREEMENT

The cooperating agencies agree to have their representatives meet at least once annually to review this statement and to make such revisions as are needed to improve programs and activities in which they have a mutual interest. Supplementary statements are to be prepared as warranted with areas of mutual cooperation to be spelled out in specific detail. Planning and conducting the annual meeting(s) shall be the joint responsibility of SHHH and RSA.

Date: _____ Name: _____
Self Help for Hard of Hearing People

Date: _____ Name: _____
Rehabilitation Services Administration

Date: _____ Name: _____
National Institute of Handicapped Research

Date: _____ Name: _____
Council of State Administrators of Vocational Rehabilitation

APPENDIX D

Americans With Disabilities Act
Section §36.303

§36.303 **Auxiliary aids and services.**

(a) *General.* A public accommodation shall take those steps that may be necessary to ensure that no individual with a disability is excluded, denied services, segregated or otherwise treated differently than other individuals because of the absence of auxiliary aids and services, unless the public accommodation can demonstrate that taking those steps would fundamentally alter the nature of the goods, services, facilities, privileges, advantages, or accommodations being offered or would result in an undue burden, i.e., significant difficulty or expense.

(b) *Examples.* The term "auxiliary aids and services" includes--

(1) Qualified interpreters, notetakers, computer-aided transcription services, written materials, telephone handset amplifiers, assistive listening devices, assistive listening systems, telephones compatible with hearing aids, closed caption decoders, open and closed captioning, telecommunications devices for deaf persons (TDD's), videotext displays, or other effective methods of making aurally delivered materials available to individuals with hearing impairments;

(2) Qualified readers, taped texts, audio recording, Brailled materials, large print materials, or other effective methods of making visually delivered materials available to individuals with visual impairments;

(3) Acquisition or modification of equipment or devices; and

(4) Other similar services and actions.

(c) *Effective communication.* A public accommodation shall furnish appropriate auxiliary aids and services where necessary to ensure effective communication with individuals with disabilities.

(d) *Telecommunication devices for the deaf (TDD's).* (1) A public accommodation that offers a customer, client, patient, or participant the opportunity to make outgoing telephone calls on more than an incidental convenience basis shall make available, upon request, a TDD for the use of an individual who has impaired hearing or a communication disorder.

(2) This part does not require a public accommodation to use a TDD for receiving or making telephone calls incident to its operations.

(e) *Closed caption decoders.* Places of lodging that provide televisions in five or more guest rooms and hospitals that provide televisions for patient use shall provide, upon request, a means for decoding captions for use by an individual with impaired hearing.

(f) *Alternatives.* If provision of a particular auxiliary aid or service by a public accommodation would result in a fundamental alteration in the nature of the goods, services, facilities, privileges, advantages, or accommodations being offered or in an undue burden, i.e., significant difficulty or expense, the public accommodation shall provide an alternative auxiliary aid or service, if one exists, that would not result in an alteration or such burden but would nevertheless ensure that, to the maximum extent possible, individuals with disabilities receive the goods, services, facilities, privileges, advantages, or accommodations offered by the public accommodation.

APPENDIX E

In-Service Training Curriculum

IN-SERVICE TRAINING CURRICULUM
WORKING WITH PERSONS WHO ARE HARD OF HEARING

Part I. Hard of Hearing: General Information

The following topics would be appropriate for any professional trainee group, regardless of discipline.

I. Scope of the Problem

- A. Definition
- B. Prevalence data by age, sex and role
- C. Financial impact

II. Basic Audiological Information

- A. Anatomy of the ear
- B. Types of hearing loss
  - 1. Conductive, sensorineural, mixed
  - 2. Unilateral and binaural
- C. Degree of hearing loss (mild to profound)
- D. Causes of hearing loss
- E. Significance of age of onset of hearing loss
- F. The audiogram and how to interpret it
- G. Aural rehabilitation
- H. Deaf vs. hard of hearing
  - 1. Cultural identification
  - 2. Communication mode

III. Special Sub-Groups

- A. Stapedectomy candidate
- B. Cochlear implant candidate
- C. Meniere's disease
- D. Tinnitus
- E. Late-deafened

IV. Psychosocial Effects of Hearing Loss

- A. On the individual
  - 1. Common feelings (anger, frustration, loss, depression, etc.)
  - 2. Fatigue resulting from extra time and energy required
  - 3. Withdrawal and other common outcomes
- B. On close personal relationships (family, friends, etc.)
- C. On employment (security, identity, etc.)

V. Communication

A. Tapes demonstrating approximations of various types of hearing losses
B. Effects of hearing loss on speech understanding
C. Importance of vision on speech recognition and speechreading
D. Communication tips
    1. For the hearing person
    2. For the person who is hard of hearing

VI. The Hearing Aid

A. Components
B. Types (ITE, ITC, Behind-the-Ear, Digital)
C. Monaurals vs. binaurals
D. Benefits and limitations
E. T-Switch and its use
F. Environmental factors that affect performance
G. Trial periods, replacement, and insurance

VII. Assistive Listening and Other Devices

A. Importance of moving the sound source as close to the ear as possible while reducing the background noise
B. Assistive listening devices
    1. Hard wired systems
    2. FM systems
    3. Infrared systems
    4. Loop systems
    5. Telephone amplifiers
C. Maintenance requirements
D. Other devices
    1. Alerting devices (alarm clock, doorbell, smoke, baby, combination, etc.)
    2. TDDs and computers
    3. Telecaption decoders and chips
    4. Cochlear implants
    5. Hearing ear dogs
E. Who decides on equipment selection and who pays

VIII. Professionals in the Hearing Health Field

A. What they do; qualifications; what to expect in a report
    1. Otolaryngologists
    2. Otoneurologists
    3. Audiologists
    4. Hearing aid dispensers
B. When to refer to mental health professionals

IX. Consumer Support Groups

A. Who belongs and what they do
   1. Self Help for Hard of Hearing People, Inc. (SHHH)
   2. Association of Late Deafened Adults (ALDA)
   3. American Tinnitus Association
B. How to interface with support groups
   1. Mutual learning
   2. VR role with chapter development assistance

Part II. Rehabilitation of Individuals Who Are Hard of Hearing

The following topics are more rehabilitation specific and intended for the audience who will be working directly with the client who is hard of hearing.

I. Psychological Prerequisites to Rehabilitation

A. Acknowledgement of reality and permanence of loss
B. Balanced attribution of cause
C. Mental abilities: capacity to handle ambiguity, flexibility, concentration without tension, good language
D. Restored feelings of security and personal power
E. Attitude toward independence: readiness to work toward shared responsibility
F. Some resolution to feelings of anger, depression, fatigue, etc.
G. Other attributes (maintenance of interests, sense of humor, etc.)

II. Counseling Individuals Who Are Hard of Hearing

A. Role of counseling
   1. Facilitating active mourning
   2. Exploring other life experiences that might contribute to the problem
   3. Assisting in regaining perspective and confidence
B. Suggested principles and techniques in counseling people who are hard of hearing
C. Strategies for teaching employability enhancement skills

III. Job Accommodation

A. Pin-pointing work related problems
B. Assessing the communication requirements of the job
C. Identification of reasonable accommodations
D. Advising employers
   1. Capabilities/potential of employees who are hard of hearing
   2. Accommodating workers who are hard of hearing (amplification, acoustical help, visual help, ALDs, staff orientation)
   3. Legal right of employees who are hard of hearing (504; ADA; OSHA)

IV. Serving the Client Who is Hard of Hearing in the Vocational Rehabilitation Process

A. Diagnosis
B. Eligibility
C. Order of Selection for Services
D. Case services
E. Postemployment services

V. Benefits

A. Workers' Compensation
B. SSI
C. Medicaid and Medicare

VI. Transitional Services

A. Identification in the schools
B. Importance of early involvement
C. The school's role in provision of diagnostics

VII. Vocational Rehabilitation Accessibility

A. Counselors
B. Receptionist/telephone operator
C. Interview/counseling rooms
    1. Free of background noise and distractions
    2. Availability of ALDs

VIII. Local Community Resources

APPENDIX F

How To Communicate With People Who Are Hard of Hearing

HOW TO COMMUNICATE WITH HARD OF HEARING PEOPLE

1. Positioning:

   a. Be sure the light, whether natural or artificial, falls on your face. (Don't stand with the sun to your back or in front of a window. Even at night, room lights will reflect in the window pane, causing glare for the lip reader.)

   b. If you are aware that the person who is hard of hearing person has a better ear, stand or sit on that side.

   c. Avoid background noise if at all possible.

2. Method:

   a. Get the person's attention before you start talking. You may have to touch the person lightly to attract attention. Face him or her directly while speaking.

   b. Speak as clearly as possible in a natural way and at a moderate pace. Don't shout! Shouting often results in distortion of speech and it displays a negative visual signal to your listener. Don't drop your voice at the end of the sentence.

   c. If the person does not understand what you said, rephrase it.

   d. When changing the subject, indicate the new subject with a word or two or a phrase. You may ask the person if he/she understood, then proceed with topic clues and perhaps gestures if the subject being discussed is visible and within range of sight.

3. Physical:

   a. Do not obscure your mouth with your hands. Do not chew and do not smoke while talking.

   b. Facial expressions are important clues to the person who is hard of hearing. Feelings are more often expressed by non-verbal communication than through words.

Communication Rules

4. Attitude:

   a. Do not become impatient.

   b. Stay positive and relaxed.

   c. Never talk about a person who is hard of hearing in his or her presence. Talk **to** them, not **about** them.

d. Treat people who are hard of hearing with respect and help build their confidence.

e. Ask what you can do to facilitate communication.

APPENDIX G

Resources

RESOURCES

GENERAL INFORMATION

Self Help for Hard of Hearing People, Inc.
7800 Wisconsin Avenue
Bethesda, MD 20814

National Information Center on Deafness
Gallaudet University
800 Florida Avenue
Washington, DC 20002

American Speech-Language-Hearing Association
10801 Rockville Pike
Rockville, MD 20802

Association of Late Deafened Adults
1027 Oakton
Evanston, IL 60202

Better Hearing Institute
Suite 700
1430 K Street NW
Washington, DC 20005

REHABILITATION SERVICES

Rehabilitation Services Administration
Deafness and Communication Disorders Branch
330 C Street SW#3221
Washington, DC 20202

National Rehabilitation Information Center
4407 8th Street NW
Washington, DC 20009

TELEPHONE/TDD/TT DIRECTORY

Telecommunications for the Deaf, Inc.
814 Thayer Avenue
Silver Spring, MD 20912

RESOURCES THROUGH TOLL-FREE TELEPHONE NUMBERS

American Speech-Language Association Help Line	800-638-8255 V/TDD/TT
Americans With Disabilities Act Information Center	800-466-4232 V/TDD/TT
Assistive Listening Devices Resource Material 7800 Wisconsin Avenue Bethesda, Maryland	301-657-2490 V/TDD/TT
Cochlear Implant Information	800-458-4999 V/TDD/TT
Hearing Aid Help Line	800-521-5247 V/TDD/TT
National Rehabilitation Information Center	800-346-2742 V/TDD/TT